Parliamentary Inquiry into ME/CFS; Outline Proposals

Preamble

Following our recent telephone conversations it is clear that

i. Your proposed Independent Inquiry will need considerable time to consider all the evidence concerning ME/CFS and scrutinise it carefully.

ii. This is an ambitious undertaking. The Inquiry team will need to engage with a massive amount of both written and oral evidence.

iii. There is much division and even conflict between some official views of the illness and also among the ME/CFS community concerning major aspects of the illness and the history of developments over at least 20-25 years with individuals and groups adopting stances that vary from aggressive to despair about the truth never being told or admitted.

iv. The Inquiry team will need to be headed by a judge/QC and its members to be seen by all ME communities as truly independent. Already there has been concern expressed about possible membership of the Inquiry team. It is important that the full details of the membership be made public with any association members may have with parliamentary, regional ME/CFS groups, and clinical centres, especially those with adherence to an "establishment" view of the illness.

v. You have already judged the APPG to be an inadequate and failing Committee which ill serves the ME/CFS communities.

vi. Mr Des Turner who chairs the APPG and has been a member for over 8 years has already been the subject of concern and anxiety by some within the ME/CFS community because of his bias towards a psychiatric understanding of ME/CFS and the use of the term myalgic encephalopathy

vii. Your reasons for not inviting the Countess of Mar to join the Inquiry team – she represents a declared viewpoint- apply with equal force to Mr Des Turner who has a known declared viewpoint that runs contrary to that of many within the ME community.

viii. It is possible that his membership could prejudice the Inquiry from the start – something that should be avoided for such an important undertaking unless counterbalanced by someone of equal stature with an opposite view.

It is important that the Inquiry is aware of my role in the current concerns of the ME/CFS community. I have been involved with this illness through my work with the 1990-1 Gulf War Veterans many of whom have been diagnosed with CFS. Over the last 8 years I have been a member of the John Richardson ME Research Group that was founded by Dr John Richardson ably supported by Dr Irving Spurr who, following Dr Richardson's death in 2002, now leads this group. I have spoken

to many groups locally and nationally and supported some individuals in a number of appeals and submissions for support and benefits and corresponded with some clinicians. I have tried to assess the scientific and medical evidence presented on all aspects of ME/CFS. I am, I believe trusted by many people with ME/CFS.

At the end of this short report I have listed people, in alphabetical order, who could make presentations to the Inquiry team of the important issues raised in this outline report. Many of them can contribute to more than one area of this report. The availability of Powerpoint facilities will facilitate speedy and efficient presentations.

I have kept the references to a minimum as these will be considerably expanded in written submissions and presentations.

Major Issues that need to be Addressed.

In my judgement and following consultation with members of the ME/CFS communities these are as follows.

1. **Nomenclature, Case Definition(s), and Disease Classification**- ME (myalgic encephalomyelitis) is a multi-system, multi-organ illness presenting with multiple symptoms. Historically ME has been associated with a prior viral infection but progressively all clinical signs have been gradually removed from the case definition leaving only persistent fatigue lasting more than 6 months as the definitive symptom.

    1. EV-ME (enterovirus Myalgic Encephalomyelitis) represents the classical form of the illness.

    2. More recently the advent of the widespread use of pesticide has provoked symptoms akin to the classical viral illness. What is the connection between the common expression of these symptoms? Different subgroups of patients have been identified and distinguished but this is ignored in the UK- why is this?

    3. The progressive removal of all clinical signs associated with the illness and the attempts to replace the term ME with CFS and even fatigue syndrome(s) which are classified as mental and behavioural disorders must be fully investigated by the Inquiry because it is here that there a lack of scientific credibility and where much anger and despair are felt by patients and those who support them.

    4. The use of the alternative name, myalgic encephalopathy also abbreviated to ME, offers a meaningless term for classification and flies in the face of the inflammatory nature of myalgic encephalomyelitis. It is part of the confusion surrounding the understanding of ME.

    5. The validity and basis of the psychiatric definitions of the illness also need to be thoroughly explored by the Inquiry team.

6. The role of the Chief Medical Officer's Report and the Medical Research Council in defining the illness and funding research and treatment centres also need close scrutiny.

Important documents cataloguing these issues from our standpoint include

Canadian Consensus Panel Criteria for M.E. *J Chron Fatigue* 2003;11:7-115. This is a major milestone for the ME/CFS community and needs to be studied carefully- a useful summary of their proposals is found in some of the documents listed below.

Marshall EP, Williams M, Hooper M. What is ME? What is CFS?- Information for Clinicians and Lawyers, 2001. Available as a download fromhttp://www.meactionuk.org.uk/

Hooper M, Marshall PD, Williams M. Response to CMO's Working Group Report, 2002 available at http://www.meactionuk.org.uk/

Hooper M, Marshall PD, Williams M. Response to MRC Research Advisory Group, December 2002 available at http://www.meactionuk.org.uk/

Hooper M and members of the ME (Myalgic Encephalitis) "The Mental Health Movement – Persecution of Patients", a briefing document for the Countess of Mar for a debate in the House of Lords, 22nd Jan 2004. Downloads of documents and the debate at

http://www.satori-5.co.uk/word_articles/me_cfs/prof_hooper_3.html- documents

http://listserv.nodak.edu/scripts/wa.exe?A2=ind0401d&L=co-cure&F=&S=&P=1313 for the debate.

Hooper M. Engaging with ME: towards understanding, diagnosis and treatment, 2003/4, – provides a useful overview of these and other issues concerning ME/CFS.

RCEP, Royal Commission on Environmental Pollution. Crop Spraying and the Health of Residents and Bystanders, Chair Sir Tom Blundell, September 2005 recognises the validity of multiple symptoms, multi-system, and multi-organ syndromes including ME/CFS, Gulf War Syndrome, and multiple Chemical Sensitivity syndrome.

Some local ME/CFS groups have produced their own literature on these issues

2. **Diagnosis and Treatment.**

1. Despite early studies that recognised the organic nature of the ME/CFS The increasing emphasis on psychiatric definitions of CFS and its use as a catch-all term has led to a confusing and all-inclusive diagnosis, ignoring the need for subtyping of the illness, and the insistence on wholly inappropriate treatments being prescribed and in some cases forced on patients as a prerequisite for benefits payments.

2. The Canadian criteria provide an abundance of clinical tests and signs that can be used in the diagnosis of ME/CFS and cover every aspect of the illness- the organs and body systems involved.

3. MRI and SPECT scans are strongly favoured by many practicing physicians and research workers. More specialised techniques that can be used to diagnose patients are also emerging.

4. Diagnosis requires a very thorough patient history and the knowledge of reliable evidence from research studies and clinical practice.

5. It is important that clinical investigations are directed and conducted using the information provided by the Canadian consensus – necessary procedures include MRI and SPECT and allied scans coupled with diagnostic endocrine, immune system and cardiovascular studies.

6. Supportive interventions need to be soundly based on both clinical and research studies. Rapid diagnosis will provide effective therapy that is less effective after long delays in diagnosis. The current 6 months period of sustained fatigue precludes early treatment and disadvantages the patient, especially the young.

7. To include ME/CFS among somatoform disorders is seen by some psychiatrists as an abuse of psychiatry.

Key literature includes

Canadian Consensus Panel Criteria for M.E. *J Chron Fatigue* 2003;11:7-115.

Chia JKS. The role of enterovirus in chronic fatigue syndrome. *J Clin Pathol* 2005;58:1126-1126.

Hyde B, Goldstein J, Levine P. The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Nightingale Research Foundation, Ottawa, 1992. This is a major source of information and should be read. Copies can be provided if needed.

Per Dalen Somatic medicine abuses psychiatry. Download at http://art-bin.com/art/dalen_en. html

Richardson J. Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and other Organ Pathologies. Haworth Medical Press, Binghampton NY, 2001.

Richardson J. Four Cases of Pesticide Poisoning Presenting as "ME", Treated with a Choline Ascorbic Acid Mixture. *J. Chronic Fatigue* 2000, 6, 11-21.

Kaushik N, Fear D, Richards SCM, McDermott CR, Nuwaysir EF, Kellam P, Harrison TJ, Wilkinson RJ,Tyrrell DAJ, Holgate ST, Kerr. Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome. *J. Clin. Pathol.* 2005;58;826-832.

Richardson J, Myalgic Encephalomyelitis: Guidelines for Doctors. *J Chronic Fatigue* 2002;10:65-80.

Jason LA, Corradi K, Torres-Harding S, Taylor RR, King C. Chronic fatigue syndrome: the need for subtypes. *Neuropsychol Rev* 2005;15:29-58.

Peckerman A, Lamanca JJ, Dahl KA, Chemitiganti R, Qureishi B, Natelson BH. Abnormal impedance cardiography predicts symptom severity in chronic fatigue syndrome.*Am J Med Sci* 2003;326:55-60.

Benefits and Insurance Claims and Assessments.

These have been the source of great anxiety, anger and despair among many ME/CFS patients.

8. The influence of the psychiatric lobby on both medical and insurance assessments is extensive and serious with some patients being compelled to undergo psychiatric and psychological programmes of cognitive behavioural therapy (CBT) and graded exercise therapy (GET). Evidence is accumulating that CBT offers no significant improvement over the short or long term, whilst GET is positively harmful for some patients.

9. CBT and GET studies are particularly confused by patient selection that meets criteria that are extremely broad and unfocussed with regard to ME/CFS.

10. Dr WRC Weir has extensive experience in preparing reports for insurance and benefits cases and can speak with authority about the difficulties experienced by many ME/CFS sufferers in making clinically supported claims.

3. **The Science of ME/CFS.**

Very exciting research studies are now appearing that unambiguously demonstrate that ME/CFS is a complex organic illness with an increasingly identified pathology. An essential requirement for any research studies is an accurate diagnosis of both patient and control groups. This emphasises the importance of the above comments on disease classification, case definitions, and diagnosis.

1. MERGE – this group works in conjunction with the world renowned cardiovascular group at the University of Dundee (Ninewells Hospital). A major figure is Dr Vance Spence a medical researcher who suffers severely with ME. They have published papers on the CDC defined patients and distinctions between different groups of patients (Gulf War Syndrome (GWS), organophosphate (OP) poisoning, and ME/CFS) with a common symptomology, unique cholinergic responses in ME patients, oxidative stress in ME patients, and have initiated and funded research studies on genes and ME/CFS, muscle activity, pain and fatigue. Their summaries of research in this field are scientifically accurate- see above.

2. Gene research, in a well defined group of ME/CFS patients has found major upregulation of genes associated with the immune system, mitochondrial function, and neuropathy target esterase, NTE. This study shows that changes in immune responsiveness are a feature of ME/CFS- something indicated in the studies when the illness first emerged. Mitochondrial dysfunction provides a physiological basis for the debilitating and overwhelming fatigue suffered by ME/CFS patients whilst the changes in the NTE gene provide an intriguing link with OP poisoning and nerve agent exposure found in GWS.

3. Dr Abhijit Chaudhri formerly at Glasgow and now at Oldchurch hospital has investigated CFS/ME using functional magnetic resonance and found changes in choline levels in the brain. A study confirmed by Professor Puri.

4. Professor Basant Puri at Imperial Medical School has also investigated other magnetic resonance changes in the brain. Other investigators have found changes in the volume of gray matter in varying regions of the brain.

There are major research groups in Europe, Canada and the USA also investigating ME/CFS who have made significant contributions through publications and conference presentations covering the areas of immunology, muscle and central fatigue, endocrinology, cardiology, and neurology.

Major literature sources include

Puri BK, Counsell SJ, Zaman R, Main J, Collins AG, Hajnal JV, Davey NJ. Relative increase in choline in the occipital cortex in chronic fatigue syndrome. Acta Psychiatr Scand. 2002;106:224-6.

Puri BK; (2004) "The use of eicosapentaenoic acid in the treatment of chronic fatigue syndrome." Prostaglandins Leukot Essent Fatty Acids volume 70 issue 4 pp. 399-401 (issn: 0952-3278).

Puri BK; Holmes J; Hamilton G; (2004) "Eicosapentaenoic acid-rich essential fatty acid supplementation in chronic fatigue syndrome associated with symptom remission and structural brain changes." Int J Clin Pract volume 58 issue 3 pp. 297-9 (issn: 1368-5031)

Cox IJ; Puri BK; (01/04/2004) "In vivo MR spectroscopy in diagnosis and research of neuropsychiatric disorders." Prostaglandins Leukot Essent Fatty Acids volume 70 issue 4 pp. 357-60 (issn: 0952-3278)

Chaudhri A and Behan PO. In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. *Prostaglandins Leukot Essent Fatty Acids* 2004;71:181-3

Hyde B, Goldstein J, Levine P. The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Nightingale Research Foundation, Ottawa, 1992. This is a major source of information and should be read. Copies can be provided if needed.

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Richardson J, Myalgic Encephalomyelitis: Guidelines for Doctors. *J Chronic Fatigue* 2002;10:65-80.

Richardson J. Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and other Organ Pathologies. Haworth Medical Press, Binghampton NY, 2001.

Richardson J. Four Cases of Pesticide Poisoning Presenting as "ME", Treated with a Choline Ascorbic Acid Mixture. *J. Chronic Fatigue* 2000, 6, 11-21.

"Breakthrough" produced by the Charity MERGE (Myalgic Encephalomyelitis Research Group for Education and support) provides useful summaries of research studies for people with ME/CFS and doctors and carers who support them. Available at www.meresearch.org.uk

4. **Research Funding.**

    1. The evidence shows that very considerable sums gave been allocated to support research studies aimed at validating the psychiatric approach to and understanding of ME/CFS, in line with national policy. Excellent research programmes seeking to investigate the organic basis of the illness have been refused funding and research has only been able to proceed through funding raised by the efforts of patients and their helpers and supporters.

    2. The policy and assessment of research proposals by the MRC need to be examined and questioned.

    3. The role of the MRC RAG and NICE in establishing the current research agenda also needs to be examined.

5. **Patient Groups Testimony, Experience, and Need.**

It is important that the voices of patients are fully heard- a failure of the CMOs working group. To that end I would suggest that

    1. The 25% Group lead by Simon Lawrence and Greg Crowhurst. This group encompasses the 25% of people with ME/CFS who are very seriously ill and are either housebound or bed bound. Whilst the incidence of ME/CFS is hard to gauge it is estimated that 1 in 250 have ME/CFS with between 1 in 1250 falling in the 25% Group.

    2. Young people with ME/CFS are of particular concern and Dr Nigel Speight with Jane Colby of TYMES trust are the best people to tell their stories and the demands faced by families with sick children.

    3. Two representative patient groups with, where possible, their accompanying physician be invited to meet with the Inquiry Team and present their evidence and stories,

Mrs Pauline Donaldson and Professor TJ Daymond Sunderland and South Tyneside ME Support Group.

Mr Geoff Bock-Brown East Anglia ME Support Group that covers Norfolk, Cambridge and Suffolk.

Many other groups will wish to contribute and it is important that these two groups are seen as representative of many and not just speaking for themselves

4. Two patients from Dr Weir's clinic.
5. RiME- Research into ME has a fine collection of case histories that the Inquiry team need to read or heard.
6. CFS Research Foundation has provided research funding for an important genetic study- their testimony in writing or orally is important.
7. MEActionuk run by Stephen Ralph provides an invaluable archive of major documents and papers- see www.meactionuk.org.uk

The inquiry should be advertised widely with invitations to all groups involved with ME/CFS to participate and present their evidence.

6. **Proposed list of people to make oral and written presentations to the Inquiry.**

Dr Abhijit Chaudhri* a neurologist with a longstanding special interest in ME/CFS, formerly at

Glasgow, now at Oldchurch Hospital, Romford, has published several papers and lectured extensively on ME/CFS

Jane Colby* – TYMES Trust for young people with ME/CFS.

Gregory Crowhurst Secretary and carer, 25% Group works closely with Simon Lawrence

Prof Malcolm Hooper a trustee of John Richardson Research Group - scientist and writer and author of numerous articles on ME/CFS and related multisymptom/multi-system/multi-organ disorders.

Professor Basant Puri* Imperial College School of Medicine – a psychiatrist with special interest in brain function and illness

Dr Nigel Speight*. A paediatrician with a longstanding interest in the treatment and care of children and young people with ME/CFS. Much used in legal cases involving children and parents as carers.

Dr Vance Spence, Director of MERGE and principal researcher with several outstanding research publications to his name working within the Medical School at the cardiovascular Unit at University of Dundee (Ninewells Hospital.)

Dr Irving Spurr MB ChB John Richardson Research Group taken over as leader of the Research Group following the death of Dr John Richardson in 2002. A special interest in enteroviruses and ME/CFS.

Dr Willie Weir a clinical specialist with long experience of caring for and supporting people with ME/CFS, particularly involved with benefit and insurance claims.

* still to be contacted.

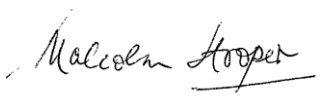
From Overseas

Dr Byron Hyde a Canadian clinician with a long involvement with patients with ME, co-editor of the major textbook and well informed about the best techniques for investigating people with ME/CFS.

Dr Bruce Carruthers a clinician who was the senior author of the Canadian Consensus and Criteria set forth to help in the diagnosis and treatment of people with ME/CFS.

I have not included many research workers and clinicians from the USA, Komaroff, Jason, Cheney, Klimas, Montero-Patarca, Natelson, Sudhholnik, and Europe De Meirleir, Le Bleu, Jadin, and Australia, McGregor, Dunstan, for obvious costing implications who could have contributed irrefutable scientific evidence. We would hope to have Professor Komaroff of Harvard present to the Inquiry if funding can be arranged in time.

I have concentrated on the UK contributors and overseas experts who are prepared to travel at their own expense to the UK.



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