INVEST IN ME CONFERENCE: 23 MAY 2008

Dr Charles Shepherd reports.....

One Birdcage Walk, a magnificent listed building just round the corner from Whitehall, was the venue for the fourth major UK conference on ME/CFS so far this year.

Patients, researchers and clinicians (who were sadly in the minority) gathered to hear a succession of speakers from both the UK and America talk about the key issues of how to sub-group people who come under the ME/CFS umbrella and the alternatives to psychiatric management.

The conference was chaired throughout the day by Professor Malcolm Hooper.

Dr Leonard Jason (Professor of Clinical and Community Psychology: De Paul University, Chicago, USA) opened the conference by looking at how important it is to develop a case definition for ME/CFS that accurately defines what this illness is in terms of how patients describe their fatigue and various other symptoms, and at the same time separates out those people who have chronic fatigue but do not have ME/CFS.

Dr Jason looked at the history of case definitions for ME/CFS, including the Canadian Criteria, but concentrated on the Fukuda et al definition, as this is the one that is used by the international research community. He went on to critically examine the new CDC empirical case definition - which grades frequency and severity of symptoms as well as disability - and how the use of this new definition has resulted in a significant increase in the estimates of how many people in America may have ME/CFS..

One of the most important messages regarding defects in the design of the current CDC case definition is that it is perfectly possible to have CFS even though the person may not have three key symptoms associated with the syndrome: cognitive dysfunction; post-exertional malaise; and sleep disturbance.

Dr Jason also described the new IACFS/ME paediatric case definition for ME/CFS and pointed out flaws in the way in which the new CDC definition had been used to conclude that childhood trauma is an important risk factor for CFS.

Dr Jonathan Kerr (Senior Lecturer in Inflammation, St George's University of London, UK) spoke about his research into gene expression and preliminary results indicating that abnormalities found so far could help to sub-group people with ME/CFS by symptoms and severity into 7 different sub-groups. These findings obviously have important implications in our search for a diagnostic test. They also provide useful information about what sort of drug treatment might be targeted at people within these different sub-groups. Clinical trials involving drugs aimed at the underlying disease process will hopefully form an extension of this research.

Ref: Kerr J et al. Seven genomic subtypes of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME): a detailed analysis of gene networks and clinical phenotypes. Journal of Clinical Pathology, 2008, 6, 730 - 739.

Dr Martin Lerner (Infectious Disease Specialist, Wayne State University School of Medicine, Michigan, USA) spoke about his experience of dealing with ME/CFS patients over a considerable period of time.

The first part of his presentation concentrated on the development of his Energy Point Index - a simple way of scoring the functional capacity of patients each time they visit a physician.

The second part of his talk was on the role of chronic herpes virus infections - cytomegalovirus (CMV); Epstein Barr virus (EBV) and human herpes virus 6 (HHV-6) - in the pathogenesis of ME/CFS and the role of antiviral drug treatments such as ganciclovir and valacyclovir in their treatment.

Dr Lerner also spoke about research which indicates that some people with ME/CFS have an involvement of heart muscle, with abnormal T wave function on an electrocardiogram, as a result of infection.

Reference: Lerner M. Valacyclovir treatment in Epstein-Barr virus subset chronic fatigue syndrome: thirty-six months follow up. In Vivo, 2007. 21, 707 - 713.

Dr Julia Newton (Senior Lecturer at the Institute of Cellular Medicine, University of Newcastle, UK) spoke about her research which is looking at the role of what is called the autonomic nervous system in ME/CFS and how abnormalities in the way in which these nerves unconsciously control heart rate and blood pressure could be the cause of some of the more disabling symptoms that are commonly reported in ME/CFS.

In simple terms Dr Newton described how the autonomic nervous system helps to maintain blood flow to the brain when we change from a horizontal (ie lying down) to vertical (ie standing up) position and that if this physiological mechanism fails it will result in feeling faint, dizzy or light headed on standing. If the autonomic dysfunction is more chronic then it could also have a role in producing cognitive dysfunction (ie problems with memory, concentration, attention span etc) and may even affect blood flow to skeletal muscle - hence the extension of this study using magnetic resonance scanning to look at they way in which people with ME/CFS produce muscular energy. Interestingly, similar disturbances in autonomic function have been found in a liver disease known as primary biliary cirrhosis - a condition that can also produce disabling fatigue.

The best way to test the autonomic nervous system is by using what is called a tilt table test - whereby the person is literally strapped to a table which moves from a horizontal to vertical position and allows changes in pulse and blood pressure to be recorded in relation to changes in body posture. Symptoms suggesting autonomic dysfunction can be assessed using the composite autonomic symptom scale (COMPASS).

Results so far indicate that a significant number of people with ME/CFS do have autonomic dysfunction. Dr Newton went on to describe how, in some cases, this might be helped by the use of drugs which can raise the blood pressure.

Ref: Newton JL et al. Symptoms of autonomic dysfunction in Chronic Fatigue Syndrome. Quarterly Journal of Medicine, 2007, 100, 519 - 526.

Dr John Chia (Infectious Disease Specialist, Torrance, California, USA) described how a common group of viruses known as enteroviruses can cause a wide variety of clinical presentations in humans. He then reviewed research that has both supported and dismissed a role for persisting enteroviral infection in the pathogenesis of ME/CFS.

His own research, which was initiated when his son became ill following an enteroviral infection, is now raising questions about whether it is right to conclude, as most doctors currently do, that persistent enteroviral infection is not a perpetuating factor in ME/CFS.

Dr Chia presented research findings that strongly support a role for persisting enteroviral infection in the intestines a small group of patients that he has very carefully evaluated. He also described the use of antiviral drugs (ie ribavarin) and immunomodulatory therapy (ie alpha interferon) in the management of these patients.

Ref: Chia J et al. Chronic fatigue syndrome is associated with chronic enterovirus infection of the stomach. Journal of Clinical Pathology, 2008, 1, 43 - 48.

Dr Irving Spurr (GP and Chairman of the John Richardson Research Group in Newcastle, UK) described his experiences over 20 years of running an ME/CFS diagnostic and treatment service in the North East of England. Dr Spurr worked with the late Dr John Richardson for many years on enteroviral infection and its role in ME/CFS. Dr Spurr also spoke about the use of intramuscular immunoglobulin.

Dr Jean Monro (Medical Director, Breakspear Hospital, Hertfordshire, UK) spoke about the role of environmental medicine in the assessment and management of people with ME/CFS.

Dr Judy Mikovits (Research Director, Whittemore-Peterson Institute for Neuro-Immune Diseases, Nevada, USA) closed the afternoon presentations by describing the need to identify biomarkers that could help with both diagnosis and treatment. Research into immune system dysfunction in ME/CFS - cytokine abnormalities in particular - is planned to take place at this new research institute.

Organising a conference such as this takes a great deal of time and effort. So I would like to say a big thank you to Kathleen McCall, Chair of Invest in ME and all her team.

- A DVD of the conference can be obtained from Invest in ME. More details on the Invest in ME website: www.investinme.org

- More information on the use of antiviral and immunomodulatory drugs, including trials on immunoglobulin and interferon, can be found in section 7:4 of 'ME/CFS/PVFS - An Exploration of the Key Clinical Issues'. This MEA booklet also contains information on some of the drugs that are being assessed in relation to autonomic dysfunction in ME/CFS.

- Problems in relation to obtaining antiviral and immunomodulatory drug treatments are covered in a Question and Answer on page xx.

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