

# International ME/CFS Conference 2008 - London

## Sub Grouping & Treatments for ME/CFS

The 3rd Invest in ME International ME/CFS Conference 2008 took place on 23rd May 2008 in London and was attended by presenters and delegates from 13 countries, from Europe, USA, Australia, New Zealand and South Korea, displaying a wealth of information to delegates from thirteen countries – from Ireland to New Zealand, from USA to Norway, from Austria to Australia.

The theme of the conference was *Sub Grouping and Treatments for ME/CFS*. After last year's conference the message went out that data was needed data to prove the organic nature of this disabling physical illness. The 2008 conference provided that data.

This year the chair was performed superbly by Professor Malcolm Hooper whose minimal but expert interventions kept the event on schedule with minimum interruption and thus enabled the conference to flow and maximise the time given to each presenter.

The atmosphere at the conference again showed the positive and forward-looking side of the ME community around the world - patients, carers and researchers who want to get better, who continue to campaign for better education and who are determined to find preventions, treatments or cures for this debilitating neurological illness. The intention to educate and publicise the need for sub grouping and treatments was proven to be correct as the experts presented their data showing clear subtypes of this illness.

This conference was dedicated to the work and memory of Dr John Richardson whose dedication to those suffering from ME is still evident today in the work of the John Richardson Research group whose chairman, Dr Irving Spurr, was a founder member of the group and was speaking at the conference.



### Introduction

Invest in ME chairman Kathleen McCall welcomed delegates from 13 different countries. This year Invest in ME invited Emeritus Professor Malcolm Hooper from Sunderland University to chair the conference and Professor Hooper accepted. He made the conference proceedings run smoothly and swiftly.

## Summary of presentations

### ***Dr Leonard Jason, Professor of Clinical and Community Psychology at De Paul University, Chicago***



Dr Jason is amongst the most prolific of all ME/CFS researchers. For more than a decade, Dr. Jason and his team at DePaul University's Centre for Community Research in Chicago, USA have worked to define the scope and impact of ME/CFS worldwide. Dr Leonard Jason gave a one hour long presentation going through the various ME/CFS case definitions (Fukuda 1994, Canadian Clinical Consensus definition 2003, The CDC Empirical Definition,

case definition, 2006) explaining how it is easy to mix different patient groups together depending on questions used in questionnaires. He gave an example of the different words the Eskimos have to describe snow and suggested there might be a need to find words to characterise the different types of fatigue people experience. Healthy people only feel one type of fatigue which is similar to flu like fatigue whereas people with ME/CFS can feel post-exertional fatigue (extreme weakness, discomfort, or sick after minimal effort), wired fatigue (feeling of over stimulation with extremely low energy), brain fog fatigue (mental impairment with confusion, disorientation, and inability to function in daily activities), flu like fatigue (feeling weak with flu like symptoms, such as high temperature) and energy fatigue (feeling of heaviness and immobilisation without energy to do anything for long periods at a time). The Canadian definition selects people with more physical symptoms and less psychiatric co morbidity than the Fukuda definition. A simple question of what a patient would like to do if they were healthy easily differentiates those suffering from depression from ME/CFS patients. People with ME/CFS come up with a long list of things they would like to do if they were healthy.

Dr Jason criticised the CDC 2005 Empirical definition for failing to make the hallmark ME/CFS symptoms such as post-exertional malaise, unrefreshing sleep and cognitive dysfunction as required symptoms for diagnosis. The Empirical definition rates the eight Fukuda symptoms by frequency and severity and the two scores are multiplied and to qualify the total score must be 25 or over. With the CDC Empirical definition it is possible for people to get an ME/CFS diagnosis based on 'role emotional' symptoms only. The symptoms are based on the last month instead of the usual at least six months of duration. Also the CDC Empirical definition expands the patient population from previous estimate of 400,000 to 4 million people which may sound impressive but is bound to mix lots of different patient groups.

**Dr Jonathan Kerr, Sir Joseph Hotung Senior Lecturer in Inflammation and Consultant in Microbiology in the Department of Cellular and Molecular Medicine at St George's University London**



Dr Kerr has been performing gene expression research and has published several papers on ME/CFS – most recently that of seven distinct sub types of ME/CFS.

Dr Kerr gave his presentation on gene expression in ME/CFS. The group's hypothesis is that there are several insults (virus infection, emotional stress, vaccination, etc) which give rise to the initial insult and then lead to the final common pathway/s. His group has confirmed results from previous pilot studies and has identified 88 differently expressed human genes in ME/CFS. There were seven different subtypes based on these 88 genes. The diseases and disorders associated with these genes are haematological, immunological, cancer, dermatological and neurological diseases.

The work involves finding a marker/s and potential treatments with existing drugs for each group of patients. e.g. Etanercept has been used on 6 patients and all 6 patients benefited markedly from the

treatment. Dr Kerr's and his team's plan is to repeat their work and compare the results with other illnesses such as depression, rheumatoid arthritis, osteoarthritis etc. The results from Dr Kerr's work clearly showed how different people with ME/CFS were compared to healthy controls.

**Dr A. Martin Lerner, an infectious disease specialist from the A. Martin Lerner Foundation, Michigan, USA**



Dr Lerner is an Infectious Diseases Specialist in Michigan, USA and holds five Patents for Diagnosis and Treatment of ME/CFS. Dr Lerner also heads the Lerner CFS Foundation which is establishing a molecular biology laboratory to develop specific diagnostic testing for subsets of ME/CFS and a training centre dedicated to the training of medical professionals in the treatment of those suffering from ME/CFS. Dr Lerner presented his long term data on 187 patients collected over 6 years, 5000 visits and 45,000 pieces of information.

Dr Lerner started the hour long presentation explaining his simple 1-10 Energy Index point score which has been validated. He uses it at every patient visit, every six weeks, to evaluate how the patient progresses. He mentioned how many patients do not rate fatigue as their most debilitating symptom. He advised against exercise until the patient feels well and his EI chart allows exercise at level nine. Biological findings point to viral aetiology.

## **Dr Julia Newton, Senior Lecturer in the Institute for Cellular Medicine, Newcastle University.**



Dr Newton is Senior Lecturer at the Institute of Cellular Medicine, Newcastle University. Dr Newton has been working on autonomic dysfunction in ME/CFS patients. She is the academic lead of the internationally renowned Cardiovascular Investigation Unit (Falls and Syncope Unit) which is arguably the largest autonomic nervous system testing laboratory in Europe. She carries out a research programme in the investigation of autonomic function in the

pathogenesis of fatigue with a research programme and founded and chairs the local multidisciplinary Fatigue Interest Group.

The talk focused on the physiological changes that occur when humans stand, and how autonomic nervous system responses to assuming the upright position may be impaired in those with CFS/ME. Symptoms on standing are a problem in 89% of those with definite ME/CFS.

Dr Newton mentioned how doctors traditionally tend to be interested in high blood pressure only but low blood pressure as experienced by 27% of ME/CFS patients meeting criteria for POTS can be a real problem. POTS can be treated with medication and Dr Newton mentioned how special tilt training can help patients with POTS to stay upright longer without symptoms. Also simple measures such as drinking enough water and adding salt to the diet can help alleviate POTS symptoms. Dr Newton's research using MR scanning has also found that people with ME/CFS generate more acid in their muscle and take longer to get rid of it after exercise than controls.

## **Dr John Chia, Infectious Disease Specialist, a clinician and researcher from Torrance, California**



Dr Chia is an infectious Diseases Specialist in California, USA and has published research on the role of enteroviruses in the aetiology of ME/CFS – an area implicated as one of the causes of ME/CFS by a number of studies. Enteroviruses can affect the central nervous system, heart and muscles, all of which is consistent with the symptoms of ME/CFS. In trials Dr. Chia's team has discovered that 82% of ME/CFS patients had high levels of enteroviruses in their digestive systems. Dr Chia's

research may result in the development of antiviral drugs to treat the debilitating symptoms of ME/CFS.

Dr Chia spoke about the role of enteroviruses in ME/CFS. Enteroviruses cause acute respiratory and gastrointestinal infections, with tropism for the central nervous system, muscles and the heart. A few European researchers (Nairn 1985, Gow et al. 1991, Youseff et al. 1990, Cunningham 1990, Douche-Aourik, Lane 2003) have shown enteroviral involvement in ME/CFS in the past but the results had not been replicated by other researchers. However, Dr Chia's recent data show that chronic enterovirus infection could play a major part in causing/triggering ME/CFS. Dr Chia emphasized the importance of RNA preservation when testing samples. Non-stabilised RNA

degrades rapidly (within hours) in blood, marrow and tissues. Dr Chia showed slides of enteroviral staining of stomach, thyroid and throat tissues and also slides of recurrent tongue ulceration which is a sign of chronic enteroviral infection. He also talked about Th1/Th2 polarization which determines the outcome of intracellular infection. Atopic diseases, steroids, vigorous exercise and past infections lead to Th2/Th1 imbalance and persistence of infection.

Dr Chia has treated patients with persistent enteroviral infection successfully with alpha interferon and ribavirin or the combination of alpha and gamma interferon.

### **Dr Irving Spurr, GP from Weardale, UK**



Dr Spurr is a GP and has over 20 years of experience of running ME/CFS diagnostic and treatment clinics. Dr Spurr worked with the late Dr John Richardson on enteroviruses and their implication in ME/CFS and is chairman of the John Richardson Research Group.

Dr Spurr talked about the implication of enteroviruses in ME/CFS from a UK clinician's point of view. Out of the 1000 new patients he had seen over 20 years 75% had genuine ME, 10% neurosis, 10% other infections

(Lyme disease, GF, SMON) and 5% pesticide induced illness. He stated that enteroviruses are spread via the water cycle. Tests had shown enteroviruses in the water in water reservoirs and these viruses are not destroyed by chlorination. Dr Spurr emphasized that early diagnosis is crucial for successful treatment. Purpose of the treatment is to rest the sick cells and he prescribes intramuscular immunoglobulins which he had found to be clinically effective. Treatment also involves stress reduction, appropriate graded activity, toxin free food and drink and choline/vitamin C.

### **Dr Judy Mikovits, Research Director at the Whittemore-Peterson Institute in Nevada, USA**



Dr. Mikovits is Research Director at the Whittemore-Peterson Institute for Neuro-immune diseases in Nevada, USA and has co-authored over 40 peer reviewed publications that address fundamental issues of viral pathogenesis, hematopoiesis and cytokine biology. She has a background in cancer research and she likened ME/CFS to cancer in that both are heterogeneous illnesses. The motto of the Whittemore-Peterson institute is 'Turning Today's Discoveries into Tomorrow's Cures' and Dr Mikovits outlined the challenges ahead and

showed the WPI's willingness to tackle the illness using the latest technology. The focus of the Institute is ME/CFS, Atypical MS, Fibromyalgia, Autism and Gulf War Illness. The Institute holds the world's largest CFS sample repository with more than 5000 samples. The current research hypothesis is that chronic inflammatory stimulation from acute and systemic infections of multiple viruses on a susceptible host genetic background leads to the pathogenesis characterised by ME/CFS. This chronic inflammation may be a precursor of lymphoma in some subgroups. The

institute also has several current research projects involving the 2-5A/ Rnase L Antiviral pathway. The overall goal of the current research program is to define viral and host parameters that correlate with distinct disease phenotypes. The long term objective is to analyse 25 cytokines and chemokines of 150 ME/CFS patients and 250 controls in order to establish normal parameters to assist proper sub typing.

### **Dr Jean Monro, Breakspear hospital, UK**



Dr Monro is Medical Director at the Breakspear Hospital and has a background in hospital general medicine, researching migraine and multiple sclerosis. Her primary areas of interest are nutritional medicine and immunology, metabolic function and environmental medicine. Dr Monro illustrated the way Breakspear hospital investigates and manages patients with ME/CFS. She outlined factors to consider in fatigue states. Efficient production and use of energy depends on several factors such as food, gastrointestinal function,

oxygen and cellular integrity. There are several tests to determine each of these pathways such as ATP test, lactulose breath test, tests for infections and stealth organisms, gut permeability etc. She explained how capillary circulation is often poor in ME/CFS patients. This can be due to several reasons such as immune complexes, infectious agents, hypercoagulation or vascular endothelial growth factor. Among other tests used by the Breakspear hospital are tests for autonomic nervous system functioning, cardiodynamics and ruling out sleep disorders. Dr Monro went on to talk about case studies which illustrated how proper diagnosis and appropriate treatment can lead to significant improvements in patients' lives.

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