



**3rd Invest in ME
International
ME/CFS Conference
2008**

Conference Summary

The 3rd INVEST in ME INTERNATIONAL ME/CFS CONFERENCE 2008

Foreword

The 3rd Invest in ME International ME/CFS Conference 2008 was held in London on 23rd May 2008. Presenters from both sides of the Atlantic displayed a wealth of information to delegates from thirteen countries – from Ireland to New Zealand, from USA to Norway, from Austria to Australia.

Both the Chief Medical Officer and the UK Medical Research Council were represented at the conference as were several charities and organisations from across the UK and Europe. An increased number of professional healthcare staff also attended this year's conference demonstrating the continuing interest and expectations of the IIME conferences.

What is ME/CFS

Myalgic encephalomyelitis (ME/CFS) is a severe systemic, acquired illness that is defined by the WHO in the ICD-10 code G93.3 as a neurological illness and officially accepted as such by the UK government. ME/CFS has clear clinical symptoms which manifest predominantly based on neurological, immunological and endocrinological dysfunction. While the pathogenesis is suggested to be multi-factorial, the hypothesis of initiation by a viral infection has been prominent.



A wide range of viruses and other infectious agents, such as Epstein-Barr Virus, Human Herpesvirus-6 and 7, Enterovirus, Cytomegalovirus, Lentivirus, Chlamydia and

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Mycoplasma have been investigated. Before acquiring the illness most patients were healthy, leading full and active lifestyles. ME/CFS most frequently follows an acute prodromal infection, varying from upper respiratory infections, bronchitis or sinusitis, or gastroenteritis, or an acute “flu-like” illness. One estimate of the number of UK citizens affected by ME/CFS is 250,000 people. This is five times the number of registered HIV/AIDS patients. It is also estimated that a quarter of people with ME/CFS are housebound, or worse. ME/CFS is now the leading cause of long term absence from school for children.



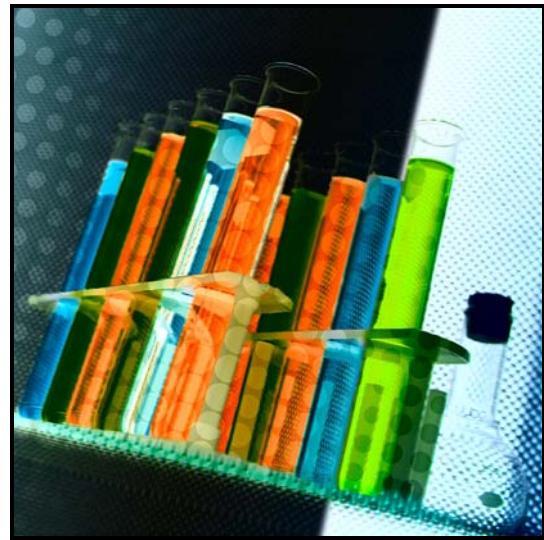
Background to liME Conferences

Invest in ME (liME) is a UK charity whose aim is to educate and raise awareness of Myalgic Encephalomyelitis (ME/CFS) and promote the acceptance of the need for a comprehensive, national strategy of biomedical research into ME/CFS.

Our conferences are CPD-accredited and consist of

biomedical research and advocacy for ME/CFS and are of interest to GPs, researchers, physicians and healthcare support staff as well as media and ME Support groups.

This year's conference was the third which we have hosted and this event has now become a permanent fixture in the ME calendar.



Theme for the liME Conference

The theme for the 3rd International ME/CFS Conference was ***Sub Grouping and Treatments for ME/CFS***. It reflected liME's belief that now was the time to progress the debate on ME/CFS and begin the sub typing of ME/CFS so that research, funding and awareness can be created to address this complex but devastating illness.

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, 2005 and The IACFS Paediatric 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

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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.

The new Paediatric Case Definition is strict and demands all symptom criteria to be met for a severe ME/CFS diagnosis, moderate ME/CFS requires 5 out of 6 symptoms and subtype variations such as ME/CFS like illness, atypical ME/CFS or in remission for those who experience idiopathic chronic fatigue but don't fully fit in the criteria.

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

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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 (presentation at IACFS Seattle 2001, Lamprecht K, et al.) 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

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advised against exercise until the patient feels well and his EI chart allows exercise at level nine. Biological findings point to viral aetiology.

Dr Lerner went on to explain cardiac involvement in ME/CFS with tachycardia at rest, abnormal cardiac wall motion and pathologic cardiomyopathy. Biopsy of heart muscle showed fibrosis, myofiber disarray and fatty infiltration.

Dr Lerner divided his 187 patients into two groups: A (124 patients) and group B (63 patients). Group A consisted of patients with single or multiple Herpes Virus Illnesses (EBV, HCMV, HHV6) and group B had co infections (Lyme disease, Babesiosis and Adult Rheumatic Fever) in addition to single or multiple Herpes Virus Illnesses. The presentation concentrated on group A patients who were treated with Valacyclovir/Valgancyclovir according to diagnosis of single or multiple infections. The mean duration of antiviral treatment was about 3 years and if there was no improvement after 1 year the treatment was stopped.

His results showed significant benefit in quality of life with this long term antiviral therapy despite length of illness or age at onset. There was no toxicity with the treatment.

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

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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.

So far Dr Chia and his team have demonstrated EV capsid protein 1 in 82% of stomach biopsies taken from more than 250 CFS/ME patients, and the finding of EV RNA and the growth of non-cytopathic EV in the same tissues provided compelling evidence for persistent EV infection.

Dr Irving Spurr, a 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

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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

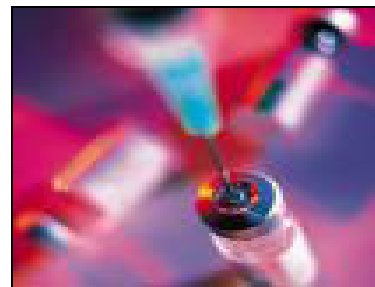
Dr Monro is Medical Director at the Breakspear Hospital and has a background in hospital general medicine, researching migraine and multiple sclerosis. Her primary areas of interest are nutritional medicine and immunology, metabolic function and environmental medicine.



Dr Monroe 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 Monroe went on to talk about case studies which illustrated how proper diagnosis and appropriate treatment can lead to significant improvements in patients' lives.

Dr Tae Park, Seoul, South Korea, also gave a poster presentation on the effect of IVIG treatment measured by improved renal function. Out of the randomly selected 125 patient 60 (50%) showed significant improvement in renal blood flow. The improvement in renal blood flow was between 35% and 60% of previous GFR. This evidence of improved renal blood flow might also be evidence of increased cerebral blood flow.

Symptoms especially fatigue, sleep disorders muscle pain and most of all cognitive function improved. There was a remarkable improvement in comprehension and concentration.



Findings

The overall message from the conference was that there are treatments available already. There have been for a number of years.

Ongoing and future research is likely to lead to real breakthroughs in understanding this illness and treating it appropriately.

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What is needed is careful and proper diagnosis to find out what patients are suffering from and tailoring of treatments to suit each patient. There is no 'one size fits all' approach to ME/CFS.

Acknowledgements

Invest in ME would like to thank the following for contributing to this very successful conference -

- Dr Leonard Jason
- Dr Jonathan Kerr
- Dr A Martin Lerner
- Dr Julia Newton
- Dr John Chia
- Dr Irving Spurr
- Dr Jean Monro
- Dr Judy Mikovits
- Professor Malcolm Hooper

Conference Comments



"What can I say? Wow and thank you yet again! A super conference and well worth the effort to get there. Brilliant speakers, great programme."

"Fantastic! The best ME conference I have been to and thanks to Invest in ME for making the price so realistic for pwme. I learned so much from this day. Keep up the good work."

"I enjoyed it all - especially being given ideas that may be able to use in practice and to be given ideas for where to look for future research to keep updated in CFS/ME practice. I have been able to gain a better understanding of CFS/ME and diagnostic criteria and changes to it. It is also very useful to be aware of research that is going on and how practices differ in UK to USA. I hope to obtain some of articles/scales mentioned and see if any can be put into practice within our CFS/ME service."

"Opened new lines for looking at literature references, in order to enhance research on CFS/ME."

"It is encouraging to see how much research is taking place and how many great medical professionals are making towards diagnosis and more recognition. Very good organisation of the event, wide variety of speakers and materials."

This conference was dedicated to the work and memory of Dr John Richardson whose dedication to those suffering from ME/CFS is still evident today in the work of the John Richardson Research group.

Conference DVD



Invest in ME have produced a DVD of the 2008 conference and this joins the DVDs from previous conferences to create an invaluable visual and audio knowledgebase for biomedical research into ME. All of the presentations from the 2008 conference, together with other material, will be available on the DVD. Price £14 including postage and packaging.

The DVD sets are professionally filmed and authored, in Dolby stereo and available in PAL (European) or NTSC (USA/Canada) format.

The 2007 and 2006 conference DVDs each consist of four discs and contain 9 ½ hours (2007 DVD set) and over 6 hours (2006 DVD set) – with all presentations plus interviews with ME presenters and news stories from TV programmes.

The Invest in ME Conference DVDs have been sold in over 20 countries and are available as educational tools – useful for healthcare staff (GPs, paediatricians, occupational therapists and others connected with the treatment of ME), researchers, scientists, educational specialists, media, ME support groups and people with ME and their carers/parents.

The 2008 DVD may be ordered from Invest in ME via this link –

<http://tinyurl.com/5fgz8q>

or via emailing meconference@investinme.org

