International ME/CFS Conference 2007 - London

Clinical Diagnosis, Treatments, Support and Research of Myalgic Encephalomyelitis

Organised by the Charity Invest in ME (www.investinme.org)

SPEAKERS:



Mr. Norman Lamb MP

Member of Parliament for North Norfolk, Liberal Democrat Shadow Health Secretary

Norman Lamb entered Parliament at his second attempt in 2001, gaining this seat from the Conservatives.

As an MP his work on local issues includes adjournment debates on: orthopaedic waiting times in Norfolk; the lack of school transport services in North Norfolk; police funding in Norfolk; funding for Further Education Colleges; the provision of care for people with dementia; and coastal erosion.

He has a particular interest in Africa: he has led Adjournment Debates on the HIV/AIDS crisis facing Africa and Asia, the controversial sale of military air traffic co7ntrol system in Tanzania and the situation in the Great Lakes region of Africa.



Dr Derek Pheby National ME Observatory, UK

Case Study – Epidemiology of ME/CFS



Mrs Ellen Piro Norwegian ME Association

Experiences from Norway

Ellen Piro is the president of the Norwegian M.E. Association.

In 1995 she circulated a worldwide petition to get the CFS name changed and she personally brought it to the Dublin CFS conference to urge the scientists to make a change.

Recently Ellen has been involved in the investigation into the use of meningitis vaccines in Norway and New Zealand and which has been connected with the cases of over 250 ME patients.

She has also contributed to the debate on the Norwegian equivalent of the NICE guidelines.



Dr Ian Gibson - MP for Norwich North

Dr. Ian Gibson has been the MP for Norwich North since his election in 1997. He is originally from Scotland and acquired a passion for all things scientific- especially biology.

He pursued his passion for science by going on to study at Edinburgh University where he gained a BSC and later on a PhD in genetics.

He served as the Dean of the School of Biological Sciences at UEA from 1991 to 1997 and headed a research team investigating various forms of cancer, including leukaemia, breast and prostate cancer. In 2003, the university made Fr. Gibson an Honorary Professor.

Dr. Gibson first stood for Parliament in 1992 and his work in Parliament and in Norwich has primarily consisted of advocacy work and pushing the government to take more notice of the role that science plays (and can play) in the UK. His scientific background has meant that he has been involved in numbers of groups and charities in Parliament.



Professor Martin Pall Professor of Biochemistry, Washington State University USA

Mechanism of Human Disease

Dr. Pall has long-term interests in biological regulatory mechanisms. His current research is focussed on a theory he has developed on the cause (etiology) of chronic fatigue syndrome and the overlapping and related conditions of multiple chemical sensitivity, fibromyalgia, and posttraumatic stress disorder. According to this theory, each of these is initiated by stresses that induce increased levels of nitric oxide and its oxidant product peroxynitrite, followed by a biochemical vicious cycle mechanism associated with chronic elevation of these two compounds. Symptoms of these conditions are produced by both nitric oxide and peroxynitrite and treatment should focus on downregulating this vicious cycle mechanism. Vitamin B-12 injections commonly used to treat these conditions are proposed to act through the action of one form of B-12 (hydroxocobalamin) which is a potent nitric oxide scavenger. Dozens of biochemical and physiological observations provide support for this theory. The most puzzling features of these conditions are explained by this novel theory.



Dr. Abhijit Chaudhuri Essex Centre for Neurological Sciences, UK

Tissue Pathology of CFS/ME

Dr. Chaudhuri was appointed as a Senior Lecturer and Consultant Neurologist in July 2000. Research on fatigue in common neurological disorders is the main theme of Dr. Chaudhuri's work. He takes special interest in myalgic encephalomyelitis (ME).

His other areas of interest are multiple sclerosis, neuroimmunity, neurological infections and adult neurometabolic diseases. Dr. Chaudhuri was responsible for examining spinal tissue from Sophia Mirza prior to the inquest into Sophia's death.

.



Dr. Vance Spence - ME Research UK

Vascular aspects of ME/CFS. Biomedical Research: where does it go from here?

Dr Vance Spence is a graduate of the Universities of London and Dundee. He was a Principal Clinical Scientist responsible for vascular services and research and, in 1997, he rejoined the University of Dundee Medical School as Honorary Senior Research Fellow in the Department of Medicine, with the objective of stimulating research into the causes of ME.



Dr Sarah Myhill GP, Wales, UK

Treatments and Diagnosis -

A GP's Perspective

Dr. Myhill is a general practitioner with a particular interest in chronic fatigue syndrome. She qualified from Middlesex Hospital Medical School with honours in 1981 and has worked in the NHS and in private practice.

Dr Myhill is interested in diagnosis in the correct sense, finding the cause of illness, not simply in treating the symptoms.

She has a special interest in treating chronic fatigue syndrome (CFS) and has consulted over 100 farmers with CFS following organophosphate poisoning and 100 women with CFS following silicone poisoning either from breast implants or injection.

Over the past twenty years Dr. Myhill estimates to have seen over 1,500 cases of chronic fatigue syndrome largely caused by viral infection. During the early years she reported these cases individually to the Medical Devices Agency.



Professor Kenny De Meirleir Free University, Brussels, Belgium

Medical Research and Treatments Updates - Treatments for ME/CFS. Integrative & Complementary Medicine.

Professor De Meirleir is a world renowned researcher and director of HIMMUNITAS Foundation Brussels and is professor of Physiology and Internal Medicine at Free University of Brussels in Belgium. He is co-editor of *Chronic Fatigue Syndrome: A Biological*

Approach, co-editor of the *Journal of Chronic Fatigue Syndrome*, and reviewer for more than 10 other medical journals. Professor De Meirleir was one of four international experts on the panel that developed the Canadian Consensus Document for ME/CFS. He assesses/treats 3,000 to 4,000 ME/CFS patients annually.

Professor Kenny L. De Meirleir, MD received his medical degree at Vrije Universiteit Brussel, Magna cum laude. His research activities in Chronic Fatigue date back to 1990. His other research activities in exercise physiology, metabolism and endocrinology have led to the Solvay Prize and the NATO research award. He is director of the Human Performance Laboratory and Fatigue Clinic at the Vrije Universiteit Brussel, as well as consultant in the Division of Cardiology and director of the cardiac rehabilitation program at Vrijie Universiteit Brussel.



Dr Nigel Speight University Hospital, Durham, UK

How Children Affects Children and Adolescents

Working as a consultant paediatrician at The University Hospital of North Durham,

County Durham, Dr Speight is the best ME children's consultant in the UK.



Dr Byron Hyde Nightingale Research Foundation,

Onset of M.E. / CFS

Thyroid Disease in ME

Dr. Byron Hyde attended the Haileybury School of Mines and worked as a geophysicist. He then did premedicine in the Faculty of Medicine and University College, University of Toronto, obtaining a degree in chemistry and nutrition. He graduated in medicine from the University of Ottawa where he was the Director and Chief of the International Exchange Program for the Canadian Association of Medical Students and Interns (CAMSI).

Dr. Hyde founded the International Summer School in Tropical Medicine. He interned at Hotel Dieu in Montreal, was a resident at St. Justine Hospital in Montreal and at the Ottawa Civic Hospital. He also studied in Munich at the University Kinderklinik and in Paris at the Necker Hospital for Children.

Dr. Hyde has authored a book on Electron Microscopy and two non-medical books. Dr. Hyde has been a physician for 25 years and has performed charitable work as a physician in Laos and the Caribbean.

He held the position of Chairman of the Ottawa Community Health Services Association, and is presently Chairman of The Nightingale Research Foundation.

In 1984, Dr. Hyde began the full-time study of the disease process then known as Myalgic Encephalomyelitis (renamed in 1986 by Dr. Gary Holmes in the USA to Chronic Fatigue Syndrome). He has worked exclusively with M.E./CFS patients since 1985. In 1988, Dr. Hyde organized an association and founded The Nightingale Research Foundation, dedicated to the study of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. He has also acted as Chairman of the 1990 Cambridge Easter Symposium and of the Workshop on Canadian Research Directions for Myalgic Encephalomyelitis / Chronic fatigue Syndrome in May, 1991, at the University of British Columbia.



Dr Jonathan Kerr Sir Joseph Hotung Clinical Senior Lecturer in Inflammation, St George's University of London

A CFS Research Group – what it does & how it works!

Genomics and proteomics of CFS/ME

Jonathan Kerr qualified in medicine from Queen's University of Belfast (1987) and completed training as a medical microbiologist (1995). He has worked as a microbiologist in Belfast, Manchester and London, taking up post as a Consultant Senior Lecturer in Microbiology at Royal Brompton Hospital / Imperial College in June 2001, and then Sir Joseph Hotung Clinical Senior Lecturer in Inflammation at St George's University of London in 2005.

His interest in Chronic Fatigue Syndrome (CFS) began during a study of the consequences of parvovirus B19 infection, when he showed that a percentage of infected cases developed CFS which persisted for several years. He is now the principal investigator in a programme of research in CFS. This involves development of a diagnostic test using mass spectrometry, analysis of human and viral gene expression in the white blood cells, and clinical trials of immunomodulatory drugs.

Dr. Jonathan Kerr and colleagues at St. George's University of London reported in the July 27, 2005 issue of the *Journal of Clinical Pathology* that a preliminary study of 25 CFS patients and 25 matched healthy controls revealed abnormalities in 35 of 9,522 genes analyzed using microarray technology. Polymerase chain reaction studies showed the same results for 16 of these genes.

The study, and its results, raises some important questions. The first of which pertains to the need for funding of microbiological CFS research. His research on gene expression has resulted in several published papers – including evidence of 7 distinct sub types of ME/CFS. Dr. Kerr also runs a ME/CFS research program. He studied the consequences of parvovirus

B19 infection in ME/CFS and showed that a percentage of infected cases developed ME/CFS which persisted for several years. He has reported 88 human genes whose dysregulation is associated with CFS, and which can be used to derive genomic CFS subtypes which have marked differences in clinical phenotype and severity.



Dr. Daniel Peterson Whittemore-Peterson Institute, Nevada, USA

Experiences of Research into ME/CFS: Past, Present & Future

Current Research Studies

Dr Daniel Peterson has been a pioneer in the treatment of ME/CFS since, together with Dr. Paul Cheney, was among the first to identify what came to be called Chronic Fatigue Syndrome in the United States. He graduated from the University of Rochester School of Medicine, Rochester, New York, in 1976 and was an intern and resident at the University of Utah Medical Center from 1976-1979. In 1979 he became a Diplomat of the American Board of Internal Medicine. He is president of Sierra Internal Medicine of Incline Village, established in 1981.



Professor Malcolm Hooper - Emeritus Professor of Medicinal Chemistry, University of Sunderland

Treatments / Clinics

Future Projects / Political issues

Professor Hooper graduated from University of London and had held appointments at Sunderland Technical College, Sunderland Polytechnic and the University of Sunderland, where he was made Emeritus Professor of Medicinal Chemistry in 1993.

Professor Hooper is a member of a number of learned bodies, including the Royal Chemical Society, the British Pharmacological Society and the Society for Drug Research (SDR), now renamed the Society for Medicines Research, where he has served on the committee for 12 years and served as Chairman for 2 years. This involved the planning and organising of major national and international conferences. He was appointed Chief Scientific Advisor to the Gulf Veterans Association (GVA) and accepted by the Ministry of Defence (MoD) as their nominee on the Independent Panel established to consider the possible interactions between Vaccines and NAPS tablets. He has also served on the Gulf Support Group convened at the Royal British Legion.

His involvement with the GVA brought contact with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/M.E.) and related disorders. Gulf War Illness/Syndrome (GWI/S) has much in common with M.E./CFS.

He is Patron of the Sunderland and South Shields M.E. Association and a member of the Newcastle Research Group, which includes eminent physicians and scientists performing research in to CFS/M.E., where one recent aspect has been the identification of organochlorine pesticide poisoning being misdiagnosed as M.E./CFS.

DVD available from Irish ME Trust