International ME/CFS Conference 2010 - London

Management, Treatments and the Latest Advances in Research into ME/CFS

Invest in ME <u>www.investinme.org</u> conference held in London in May 2010 include the following speakers:

Dr Judy Mikovits, Research Director Whittemore -Peterson Institute, Nevada, USA

Dr. Mikovits obtained her Ph.D. in Biochemistry and Molecular Biology from George Washington University and spent more than 20 years at the National Cancer Institute in Frederick MD where she investigated mechanisms by which retroviruses dysregulate the delicate balance of cytokines in the immune response.

This work led to the discovery of the role aberrant DNA methylation plays in the pathogenesis of HIV. Later in her career at the NCI, Dr. Mikovits directed the Lab of Antiviral Drug Mechanisms (LADM) a section of the NCI's Screening



Technologies Branch in the Developmental Therapeutics Program. The LADM's mission was to identify, characterize and validate molecular targets and to develop high-throughput cell-based, genomic and epigenomic screens for the development of novel therapeutic agents for AIDS and AIDS-associated malignancies (Kaposi's sarcoma).

She is Research Director at the Whittemore Peterson Nevada CFS centre for Neuro-Immune disorders and has co-authored over 40 peer reviewed publications that address fundamental issues of viral pathogenesis, hematopoiesis and cytokine biology. Formally trained as a cell biologist, molecular biologist and virologist, Dr. Mikovits has studied the immune response to retroviruses and herpes viruses including HIV, SIV, HTLVI, HERV, HHV6 and HHV8 with a special emphasis on virus host cell interactions in cells of the hematopoietic system including hematopoietic stem cells (HSC).

Dr Mikovits was co-author of the "Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with Chronic Fatigue Syndrome" research paper in October 2009 in Science magazine.

Professor Brigitte Huber PhD – Tufts Medical School, Boston, Massachusetts.

Brigitte Huber, B. A, Biology University of Zurich, Switzerland M.Sc., Pharmacology, University of Basel, Switzerland, Ph.D., Immunogenetics, University of London, England Postdoctoral Training, Harvard Medical School, Boston, MA Professor of Pathology

Professor Huber studied immunogenetics at University of London and is currently Professor of Pathology at Tufts University, Boston, USA.

Professor Huber joined the faculty of Tufts Medical School in 1977, and her laboratory has investigated the cellular



and molecular mechanisms involved in the immune response since that time.

She has studied the presence of retrovirus HERV K-18 as a marker for those who might develop ME/CFS after an acute infection such as mononucleosis. Her research shows that EBV induces the HERV K-18 envelope gene to trigger the expression of a specific superantigen and that there are more HERV K-18 alleles in post-mono ME/CFS patients than in controls.

Dr Jonathan Kerr – Clinical Senior Lecturer in Inflammation, St George's University of London.

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 Paul Cheney MD, PhD - Medical Director of the Cheney Clinic in Asheville, North Carolina, USA

Dr. Paul Cheney, MD, PhD, is Medical Director of the Cheney Clinic in Asheville, North Carolina.

For more than 25 years, Dr. Cheney has been a pioneering clinical researcher in the field of ME/CFS and has been an internationally recognized authority on the subject of ME/CFS.



He has published numerous articles and lectured around the world on ME/CFS. Dr. Cheney has been interested in many aspects of ME/CFS, and is author or co-author of numerous publications and scientific presentations in a range of fields relevant to the illness.

While practicing in Lake Tahoe in 1984-1987, Dr. Cheney, along with Dr. Dan Peterson, helped lead a research effort with the NIH, the CDC and Harvard University School of Medicine studying a localized outbreak of what would eventually be known as ME/CFS. He was a founding Director of the American Association of CFS (now the International Association for CFS/ME).

More recently, Dr. Cheney has been engaged in investigating the cardiac function of CFS patients, using Impedance Cardiography and Doppler Echocardiography. According to his paper presented at the 2007 IACFS/ME conference, "Chronic Fatigue Syndrome patients exhibit evidence of diastolic dysfunction at a level well above that reported for control populations of the same age. Energy dependent diastolic dysfunction would appear to be a hallmark of CFS and supports the hypothesis that CFS is a syndrome of cellular energy deficiency."

Since 1990, Dr. Cheney has headed the Cheney Clinic, presently located in Asheville, NC. The Cheney Clinic specializes in evaluating CFS patients and has expertise in diagnosis, disability support for and treatment of chronic fatigue syndrome. No single clinic has drawn as many CFS patients (currently over 5,000) from as many states (48) and foreign countries (22) as has the Cheney Clinic.

The Cheney Clinic has evaluated over 8,000 patients from 48 states and 24 foreign countries and participated in an FDA-approved multi-center, a biological response pharmaceutical drug trial using Ampligen, a biological response modifier.

Dr John Chia - Infectious disease specialist practicing in Torrance, California, USA.

Dr Chia is an infectious disease specialist practicing in Torrance, California, USA and has published research recently syndrome associated (Chronic fatique with chronic enterovirus infection of the stomach) on the role of enteroviruses in the aetiolgy of ME/CFS – an area which has been implicated as one of the causes by a number of studies. There are more than 70 different types of enteroviruses that can affect the central nervous system, heart and muscles, all of which is consistent with the symptoms of of ME/CFS. By analyzing samples stomach tissue from 165 patients with



CFS, Dr. Chia's team discovered that 82% of these individuals 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 Nancy Klimas - University of Miami School of Medicine

Dr Nancy Klimas MD is a Professor of Medicine, Psychology, Microbiology and Immunology at the University of Miami School of Medicine. She is the University's director of the Allergy and Immunology Clinic as well as Director of Research for the Clinical AIDS/HIV Research at the Miami Veterans Affairs Medical Centre.

She is a member of the federal CFS Advisory Committee (CFSAC) and former President and current Board Member of the International Association of CFS/ME (IACFS/ME) and a founding editor of the Journal of Chronic Fatigue Syndrome.

Dr Klimas has been a leader in the field of ME/CFS research for many years and recently Dr Klimas opened a model clinic for CFS patients with the aim to treat patients as well as train doctors.



Dr Klimas has published over a 130 peer reviewed scientific papers.

As the principal investigator of one of the NIH sponsored CFS Research Centers she leads a multidisciplinary research team representing the fields of immunology, autonomic medicine, neuroendocrinology, behavioral psychology, rheumatology, nutrition, and exercise physiology. The University of Miami CFS Research Center is exploring interactions between the immune, autonomic and neuroendocrine.

Professor Nora Chapman PhD - Professor of Pathology and Associate Professor, University of Nebraska

Professor Nora Chapman is a Research Scientist at the University of Nebraska Enterovirus Research Laboratory and Associate Professor at the University of Nebraska Medical Centre.

Professor Chapman studies persistent coxsackie infections in murine models of chronic myocarditis and dilated cardiomyopathy.

She and her associates have demonstrated that selection of defective enterovirus in heart and other tissues leads to persistent infections despite active antiviral immune responses.

Dr. Chapman is presently studying the mode of selection of these viruses and the effects of replication of these viruses upon infected cell function.



Dr. Chapman and her associates at the University of Nebraska are further investigating Dr. John Chia's work in regards to enterovirus in the gut biopsies.

Professor Leonard Jason PhD - Center for Community Research, DePaul University, Chicago

Professor. Leonard Jason, Ph.D., is among the most prolific of all CFIDS researchers. For more than a decade, Professor Jason and his team at DePaul University's Centre for Community Research have worked to define the scope and impact of CFS/ME worldwide.

Professor Jason is Vice President of the International Association for Chronic Fatigue Syndrome (now the IACFS/ME) and has been a key driver of CFS research since 1991, and is uniquely positioned to support collaboration between CFS researchers, patients, and government decision makers. His studies have shown that the direct and indirect costs of ME/CFS amount to \$20 billion in the U.S. each



year, and more than 1 million people suffer from ME/CFS as opposed to the estimated 20,000 people originally reported by the CDC (Centers for Disease Control and Prevention).

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

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.

He has served at many UK universities as well as in India and Tanzania.



He has inaugurated links with Indian research institutions and universities and celebrated 25 years of productive and on-going links which have, particularly, involved the design and development of new drugs for tropical diseases and an exploration of natural products associated with Ayurvedic medicine. He has published some 50 papers in peer-reviewed journals in the field of medicinal chemistry together with major reviews on the Chemotherapy of Leprosy, the Chemistry of Isatogens.

Edited one book on the Chemotherapy of Tropical Diseases.

He acted as a referee for a number of important journals and served on one editorial board. He has served on committees of the Council for National Academic Awards (CNAA), the World Health Organisation (WHO) and the Science and Engineering Research Council (SERC).

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.

He has addressed meetings of the Pesticide Exchange Network and consulted to the Organo-Phosphate Information Network (OPIN).

He worked with the Autism Research Unit (ARU) at the University of Sunderland for over 20 years, leading to involvement in biochemical studies to offer help, support and treatment for people with autism. This has also lead to research and urine-analysis of Indolyl-Acroyl-Glycine (IAG), which is an unusual metabolite found in excess of 90% of people examined in different groups of GWV, M.E./CFS and Organo-Phosphate (OP) poisoning sufferers.

DVD available from Irísh ME Trust