

# International ME/CFS Conference 2009 - London

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

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The 4th International ME/CFS Conference 2009 took place on 29th May 2009 in London and was attended by presenters and delegates from 14 countries and four continents.

The focus of the conference for 2009 was *Severe ME*, an attempt to raise more awareness of severe ME - a group of patients who are not represented in research trials and misunderstood by healthcare services. Many believe that studying severe ME will yield treatments and cures for this illness and have repercussions for other services including management of ME.

Following the successful IIME International conference in London in May 2008 which dealt with Sub Grouping and Treatments of ME/CFS the 2009 conference looked at the subjects of

- the ME Clinic
- diagnosis of ME/CFS
- treatments for ME/CFS
- epidemics of ME/CFS
- news from the latest biomedical research into ME/CFS

The conference was robustly chaired by Professor Jonathan Brostoff whose knowledge of the area was used frequently in the question sessions.



**Professor Jonathan Brostoff** is Senior Research Fellow and Professor Emeritus of Allergy and Environmental Health at Kings College, London. He was the Foundation Professor of Allergy and Environmental Health and Director of the Centre for Allergy Research at University College London. Whilst at University College Hospital he was Physician in charge of the Allergy Clinic. Professor Brostoff was involved in one of the few, and much-quoted Spect scan studies of ME patients [Brainstem perfusion is impaired in patients with chronic fatigue syndrome. Costa DC, Tannock C and Brostoff J. *Quarterly Journal of Medicine* 1995;88:767-773]

It was our pleasure to have Hillary Johnson as our guest in London for the Invest in ME pre-conference presentation on CDC's influence on ME research throughout the world. The presentation was impressive and shocking, telling some of the inside story of how ME has been manipulated by a government agency. This has so many parallels to the concerted campaign to misinform which has occurred in the UK over the years.



The Whittemore-Peterson Institute for Neuro-immune Diseases was represented with Annette Whittemore giving the conference keynote speech, showing this amazing development. Dr Dan Peterson gave a comprehensive lecture based on his 25 years of clinical experience and the solid research being performed at the WPI. This was followed by a presentation showing the dynamics and power of science by the WPI's research director Dr Judy Mikovits.



**Annette Whittemore**, Founder and President of the Whittemore Peterson Institute for Neuroimmune Diseases, Reno, Nevada, USA. The Institute will be built on the medical campus of the University of Nevada. Its mission is to serve those with complex neuro-immune diseases such as ME/CFS, viral induced central nervous system dysfunction and fibromyalgia. Annette Whittemore graduated in Elementary and Special Education at the University of Nevada and taught children with neuro-cognitive deficits, such as those

found in autism, ADD, and learning disabilities. As the director of the current operations at the Institute Annette supports the basic and clinical research program, and actively recruits physicians and other support personnel for the Institute.

Dr Dan Peterson is Medical Director, Whittemore Peterson Institute, Reno, Nevada, USA. With over 25 years of medical practice, Dr Daniel L. Peterson has become a sought-after internist for diagnosing difficult and complex medical cases. When several patients in Incline Village became ill with symptoms that resembled persistent mononucleosis, Daniel Peterson was one of the first physicians to recognize an outbreak of what is known as Chronic Fatigue Syndrome (ME/CFS). He became a pioneering physician and researcher in understanding



the biological characteristics and methods for diagnosing, managing and treating ME/CFS. He has also performed major studies of Ampligen as a treatment for ME/CFS, and studying the possible role of human herpes virus 6 (HHV-6) in CFS patients.

**Dr Judy Mikovits** 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. Dr. Mikovits spent more than 20 years at the National Cancer Institute, 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).

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, HTLV1, 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.

Head of the recently opened ME-centre at Ullevål University Hospital, Oslo, Norway, **Dr Barbara Baumgarten** has seen ME patients in her private practice since 1997 and has had responsibility for specialised medical services for ME patients. The ME Centre in Oslo is unique in that patients have been closely involved in its formation. Dr Baumgarten was born in Hamburg, Germany, and moved to Norway in 1980. Since 1996 she has had her own practice and has been seeing patients with ME since 1997.



From April 2006 she has been working one day a week as a GP at the department for infectious diseases, Ullevål University Hospital, Oslo. Her work there was to look at the need of specialized medical services for ME-patients. That has resulted in a new ME-clinic. Since August 2008 her main job at Ullevål University Hospital has been leader for the new ME-center, which was officially opened at December 11<sup>th</sup> 2008.

Dr Baumgarten showed us what can be done with public funds when politicians are supportive and patients' voice is being listened to. The importance of defining the patient base carefully using the Canadian consensus document was made clear and she confirmed the inadequacies of the NICE guidelines for diagnosis.

**Dr Jonathan Kerr** qualified in medicine from Queen's University of Belfast (1987), and completed training as a medical microbiologist (1995). Dr Kerr 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.

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.

**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 De Meirleir is co-author of the book '*Chronic Fatigue Syndrome: A Biological Approach*' and his published works cover many aspects of ME/CFS. Current research involves the gut and ME/CFS.

Professor De Meirleir preceded his conference presentation with a press conference in London on the day before (May 28, 2009) entitled "ME: End of an Era of Medical Negation" unveiling his findings from recent research which has included examining many patients in Norway and displayed conclusions regarding the complex mechanisms of ME/CFS pathogenesis, a diagnostic test, and directions for therapeutic strategies.

**Dr John Chia** is an infectious disease specialist practicing in Torrance, California, USA and has published research recently (*Chronic fatigue syndrome associated with chronic enterovirus infection of the stomach*) on the role of enteroviruses in the aetiology 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 ME/CFS. By analyzing samples of 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 Chia showed us his excellent, solid research on enteroviruses which is confirming previous work done in the UK. He is concentrating his efforts in finding antiviral therapy against enteroviruses. He has found Oxymatrine to be beneficial for about 53% of his patients.

**Professor Garth Nicolson** is President, Chief Scientific Officer and a Research Professor at the Institute for Molecular Medicine, Laguna Beach, California, USA. Conjoint Professor, Faculty of Science and Technology, University of Newcastle, Australia. Professor of Integrative Medicine, Capital University of Integrative Medicine, Washington DC.

Professor Nicolson has published over 550 papers, three of them current content citation classics, and his recent publications include: Chronic Fatigue Syndrome patients subsequently diagnosed with Lyme Disease *Borrelia burgdorferi*: evidence for *Mycoplasma* species co-infections; Chronic infections in neurodegenerative and neurobehavioral diseases; New emerging infections: Their development, testing and resulting disease.

Professor Nicolson gave a very good overall lecture on the role of chronic infections and complex illnesses. His presentation was full of information to show the difficulties researchers and clinicians are faced with when meeting this group of patients.

**Professor Harald Nyland** - Department of Neurology, Haukeland University Hospital, Bergen, Norway.

Professor Nyland has seen several thousand ME patients, among them many severely ill. His recent research involves an ME/CFS Epidemic Following a Giardia lamblia Infection in Bergen. Professor Nyland was knighted in 2007 for his services of over 30 years for MS patients in Norway.

Professor Nyland based his lecture on two recent epidemics in Norway. This has given researchers there a chance to do follow up studies on the patients who have remained ill with ME like illness. One outbreak was due to Giardia parasite and the other due to Legionella bacterium.

**Professor Basant K. Puri** is both a medical practitioner, working as a consultant at Hammersmith Hospital in London, and a senior scientist, working at Imperial College London. He is head of the Lipid Neuroscience Group at Imperial College and is the author of over 130 peer-reviewed medical and scientific papers and over 30 books.



*DVD available from Irish ME Trust*