Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Winter 2009

Future dates

Morning meet – Monday 15th March 2010 – 10.30am
Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ
The hotel, which has plenty of parking, is near the Royal Surrey County Hospital. At the roundabout before the hospital, turn left into the hotel car park. They have a large foyer area with plenty of comfortable sofas and large coffee tables.

Evening meet – Tuesday 20th April 2010 – 7.30pm
Worplesdon Place Hotel, Perry Hill, Worplesdon, Guildford, Surrey, GU3 3RY
There is a wide range of food and drink available (e.g. steak, chicken, fish and lamb grills and salads). This former country house has been fully refurbished in later 2007 to combine it's traditional features with more modern facilities. The Hotel offers a large beer garden which features a lake and it's own resident duck family.

Annual General Meeting
Wednesday 19th May 2010 – 4pm
The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU.
Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham). Food available includes: wood fired pizzas, spit roast chickens, plenty of fresh fish and the finest steaks.

Aside from a chance to generally chat the Annual General Meeting (AGM) is used to review the actions of the group over the last year and decide on our direction in 2010 & 2011. All are welcome.

Group website updated

Our group website: www.rescue.f2s.com was originally created using Microsoft Frontpage. As a result it would only work correctly with Internet Explorer.

The website has been recreated using Serif Webplus 10 and now works with all Internet browsers.

The password for the member's area, which contains all of our past newsletters is: letmein

“UK study publication does not impact XMRV research”

by Whittemore-Peterson Institute (WPI) News Release

Recent UK studies of XMRV in ME found no XMRV. Parts 1 & 2 below are the response of the WPI, the originators of the initial finding of XMRV in ME.

Part 1 - (January 15, 2010)

RENO, NV - In October 2009, together with the Cleveland Clinic and National Cancer Institute, the Whittemore Peterson Institute published findings in Science regarding the discovery of XMRV in the blood of Chronic Fatigue Syndrome (CFS) patients. The testing method, validated in multiple other labs using positive control samples, uses a unique process that was extensively peer reviewed before publication and provides the most accurate results available.

- This virus culture test is the same method used in the Science publication, and is the only scientifically validated methodology to find XMRV.

- Some labs, including the recent study published in the UK, have used non-validated PCR [polymerase chain reaction] and whole blood PCR assays. At this time no single PCR or whole blood assay alone has been validated as accurately detecting XMRV, and is therefore not an appropriate way to study or diagnose the presence of the virus.

Article continued: http://www.wpinstitute.org/news/docs/WPI_pressrel_011410.pdf

Part 2 - (February 18, 2010)

February 18, 2010: WPI is aware of the recent UK study that was unable to detect the presence of XMRV in any CFS patient samples. Although researchers at the WPI were not involved in this project, our work in XMRV continues with researchers around the world. We look forward to the results of studies which replicate the methods used in the original research described in the journal Science in October, 2009.

Information regarding XMRV studies

1. The authors of the Science paper established the existence of XMRV as an infectious human blood borne retrovirus for the first time in blood of patients diagnosed with Chronic Fatigue Syndrome (CFS). Previous studies had established the presence of XMRV sequences and protein in human prostate tissue.

2. In the Science paper, the presence of XMRV in well-characterized patients with CFS was established using multiple technologies:

a) PCR on nucleic acids from un-stimulated and stimulated white blood cells;
b) XMRV protein expression from stimulated white blood cells;
c) Virus isolation on the LNCaP cell line; and
d) A specific antibody response to XMRV.

3. The authors of the two UK studies did not attempt to “replicate” the WPI study. Replication requires that the same technologies be employed. The WPI sent reagents and information to several groups of researchers in an effort to support their replication studies. Neither UK study requested positive control blood, plasma or nucleic acids from the WPI.

4. The collection, preparation and storage of DNA were completely different between the Science and UK papers. The latter studies do not show data on blood harvesting or storage. Nor do the studies disclose the quantity of isolated cells. Insufficient number of cells analyzed may result in failure to detect a low copy virus like XMRV, regardless of the sensitivity of the assay. Neither UK study provides detail to allow interpretation of how many white blood cells were analyzed.

5. Patient population selection may differ between studies.

6. The UK authors were unable to detect XMRV, even though 4% of healthy individuals were found to be infected in the US. Japanese scientists detected XMRV in 1.7% in healthy blood donors in Japan. The two previously identified human retroviruses have distinct geographical distributions.

7. Perhaps the most important issue to focus on is the low level of XMRV in the blood. XMRV is present in such a small percentage of white blood cells that it is highly unlikely that either UK study's PCR method could detect it using the methods described. Careful reading of the Science paper shows that increasing the amount of the virus by growing the white blood cells is usually required rather than using white blood cells directly purified from the body. When using PCR alone, the Science authors found that four samples needed to be taken at different times from the same patient in order for XMRV to be detected by PCR in freshly isolated white blood cells. More importantly, detection methods other than PCR showed that patients whose blood lacks sufficient amount of XMRV detectable by PCR are actually infected. This was proven by the isolation of viral proteins and the finding of infectious XMRV isolated from the indicator cell line LNCaP. The authors of the Retrovirology paper admit that their neutralization assay did not detect bacterially expressed XMRV gag and that positive control sera was needed to validate their assay. The WPI's monoclonal antibodies specifically and sensitively completed the immune response demonstrating the assays sensitivity and specificity for XMRV envelope.

Simply stated the only validated reliable methods for detecting XMRV in CFS patients, to date, are the methods described in Science. Failure to use these methods and validated reagents has resulted in the failure to detect XMRV. A failure to detect XMRV is not the same as absence of this virus in patients with CFS.

Source: http://www.wpinstitute.org/news/news_current.html

Cognitive functioning in CFS: A meta-analysis

Source: Psychological Medicine, Jan 2010, by SJ Cockshell, JL Mathias,

Background: Cognitive problems are commonly reported in persons with chronic fatigue syndrome (CFS) and are one of the most disabling symptoms of this condition. A number of cognitive deficits have been identified, although the findings are inconsistent and hindered by methodological differences.

The current study therefore conducted a meta-analysis of research examining cognitive functioning in persons with CFS in order to identify the pattern and magnitude of any deficits that are associated with this condition.

Method: A comprehensive search of the PubMed and PsycINFO databases for studies that examined cognitive functioning in CFS between 1988 and 2008 identified 50 eligible studies. Weighted Cohen's d effect sizes, 95% confidence intervals and fail-safe Ns were calculated for each cognitive score.

Results:

- Evidence of cognitive deficits in persons with CFS was found primarily in the domains of attention, memory and reaction time.
- Deficits were not apparent on tests of fine motor speed, vocabulary, reasoning and global functioning.

Conclusions: Persons with CFS demonstrate moderate to large impairments:

- In simple and complex information processing speed,
- And in tasks requiring working memory over a sustained period of time.

Source: Psychological Medicine, Jan 5, 2010.pp 1-15. PMID: 20047703, by Cockshell SJ, Mathias JL. School of Psychology, The University of Adelaide, South Australia, Australia. [E-mail: jane.mathias@psychology.adelaide.edu.au]

Recommendations for a CFS or FM patient who's facing surgery?

by Dr. Charles Lapp, MD, January 15, 2010
Source: http://www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15094

Q: I will be having surgery to remove some fibroids soon, and neither my doctor nor the surgeon seem to know anything about ME/CFS or FM. I remember reading that there are things doctors can do to reduce possible complications and recovery time. Could you point me to something I can share with my doctors?

A: The following information was developed to reduce the risk of surgical procedures for ME/CFS/FM patients. It is evidence-based, with sources, and is meant to be shared with the patient's professional healthcare team.

Recommendations for persons with ME/CFS (or Fibromyalgia) who are anticipating surgery

Basically CFS is a disorder characterized by severe debilitating fatigue, recurrent flu-like symptoms, muscle pain, and neurocognitive dysfunction such as difficulties with memory, concentration, comprehension, recall, calculation and expression. A sleep disorder is not uncommon.

- All of these symptoms are aggravated by even minimal physical exertion or emotional stress, and relapses may occur spontaneously.

- Although mild immunological abnormalities (T-cell activation, low natural killer cell function, dysglobulinemias, and autoantibodies) are common in CFS, subjects are not immunocompromised and are no more susceptible to opportunistic infections than the general population.

- [Recent research indicates antibodies to the XMRV retrovirus may be present in the blood of some CFS patients,* and] it is not recommended that the blood or harvested tissues of patients be used in others.

- Intracellular magnesium and potassium depletion has been reported in CFS. For this reason, serum magnesium and potassium levels should be checked pre-operatively and these minerals replenished if borderline or low. Intracellular magnesium or potassium depletion could potentially lead to cardiac arrhythmias under anesthesia.

- Up to 97% of persons with CFS demonstrate vasovagal syncope (neurally mediated hypotension) on tilt table testing, and a majority of these can be shown to have low plasma volumes, low RBC mass, and venous pooling. Syncope may be precipitated by cathecholamines (epinephrine), sympathomimetics (isoproterenol), and vasodilators (nitric oxide, nitroglycerin, a-blockers, and hypotensive agents). Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure.

- Allergic reactions are seen more commonly in persons with CFS than the general population. For this reason, histamine-releasing anesthetic agents (such as pentothal) and muscle relaxants (curare, Tracrium, and Mevacurium) are best avoided if possible. Propofol, midazolam, and fentanyl are generally well-tolerated.

- Most CFS patients are also extremely sensitive to sedative medications - including benzodiazepines, antihistamines, and psychotropics - which should be used sparingly and in small doses until the patient's response can be assessed.

- Herbs and complementary and alternative therapies are frequently used by persons with CFS and FM. Patients should inform the anesthesiologist of any and all such therapies, and they are advised to withhold such treatments for at least a week prior to surgery, if possible. Of most concern are:

    Garlic, ginkgo, and ginseng (which increase bleeding by inhibiting platelet aggregation);

    Ephedra or ma huang (may cause hemodynamic instability, hypertension, tachycardia, or arrhythmia),

    Kava and valerian (increase sedation),

    St. John's Wort (multiple pharmacological interactions due to induction of Cytochrome P450 enzymes),

    Echinacea (allergic reactions and possible immunosuppression with long term use).

- The American Society of Anesthesiologists recommends that all herbal medications be discontinued 2 to 3 weeks before an elective procedure. Stopping kava may trigger withdrawal, so this herbal (also known as awa, kawa, and intoxicating pepper) should be tapered over 2 to 3 days.

- Finally, HPGA Axis Suppression is almost universally present in persons with CFS, but rarely suppresses cortisol production enough to be problematic. Seriously ill patients might be screened, however, with a 24-hour urine free cortisol level (spot or random specimens are usually normal) or Cortrosyn stimulation test, and provided cortisol supplementation if warranted. Those patients who are being supplemented with cortisol should have their doses doubled or tripled before and after surgery.

Summary recommendations

1. Ensure that serum magnesium and potassium levels are adequate.
2. Hydrate the patient prior to surgery.
3. Use catecholamines, sympathomimetics, vasodilators, and hypotensive agents with caution.
4. Avoid histamine-releasing anesthetic and muscle-relaxing agents if possible.
5. Use seating drugs sparingly.
6. Ask about herbs and supplements, and advise patients to taper off such therapies at least one week before surgery.
7. Consider cortisol supplementation in patients who are chronically on steroid medications or who are seriously ill.
8. Relapses are not uncommon following major operative procedures, and healing is said to be slow but there are no data to support this contention.

I hope that you have found these comments useful, and that they will serve to reduce the risk of surgical procedures.

Yours truly,
Charles W. Lapp, MD:
Director, Hunter-Hopkins Center, P.A.
7421 Carmel Executive Park Drive, Suite 320
Charlotte, NC 28226
Telephone (704) 543 9692; Fax (704) 543-8547
Website: www.drlapp.net
- Assistant Consulting Professor at Duke University Medical Center
- Diplomate, American Board of Internal Medicine
- Fellow, American Board of Pediatrics
- American Board of Independent Medical Examiners

The 5th Invest in ME International ME/CFS Conference 2010

24th May 2010 09.00 -17.30
One birdcage walk, Westminster, London

(CPD accreditation pending)

(The order form is the following 4 pages)

Conference speakers

Dr. Judy Mikovits obtained her Ph.D. in Biochemistry and Molecular Biology from George Washington University. 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.

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

Tufts Medical School, Boston, Massachusetts, USA
Professor Huber studied immunogenetics at University of London and is currently Professor of Pathology at Tufts University, Boston, USA. Dr. 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. She hopes to identify other subsets among CFS patients.

Dr Jonathan Kerr is Sir Joseph Hotung Senior Lecturer in Inflammation, St George's University of London. Dr. Kerr is now the principal investigator in a programme of research in ME/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. He has recently published research identifying distinct subtypes in patients with ME/CFS.

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 and is author/co-author of numerous publications and scientific presentations about ME/CFS.

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 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 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 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 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 Jason has been among the most prolific of all ME/CFS researchers. For more than a decade, Professor Jason and his team at DePaul University's Centre for Community Research in Chicago have worked to define the scope and impact of ME/CFS worldwide. Professor Jason was 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).

5th International IiME ME/CFS Conference 2010

Registration Form

24th May 2010 - One Birdcage Walk, Westminster, London

Post to: **Invest In ME, PO Box 561, Eastleigh, Hants SO50 0GQ**

Personal Information			
Name			
E-mail			
Phone		Fax	
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Organisation (*if appropriate*)			
Indicate if Hotel Required		Wheelchair place requested (*see below*)	

Ticket Details

Choose one ticket option below:			until 15th March 2010	after 15th March 2010
☐	Concessionary rate	For people with M.E. or their immediate carers	£35	£40
☐	Student rate	For students	£35	£40
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☐	Sponsor a GP rate	For GPs and healthcare staff registered via a local ME/CFS Support Group	£80	£100
☐	Professionals	For professional healthcare staff and others	£115	£130

Conditions (*please read below*)

Email: meconference@investinme.org
Website: www.investinme.org
Tel: 02380 251719 or 07759 349743

5th International IiME ME/CFS Conference 2010
Registration Form
24th May 2010 - One Birdcage Walk, Westminster, London

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One completed Registration Form is required for each individual wishing to attend.
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Concession Rates are offered to individuals who are individual ME Sufferers or their carers, and also to students. These concessionary places are limited and will be dealt with on a *first-come-first-served* basis. We will be maintaining a priority waiting list for those who, initially, are not able to obtain a place.

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ME symptoms and impact by Ashy Sheela

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ME symptoms

Impact