Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Spring 2011

Future dates

Morning meeting – Monday 23rd May – 11am
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 meeting – Friday 17th June – 7pm
The Seahorse - 52-54 The Street, Shalford, Guildford, 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. Having an excellent chef ensures good food.

Afternoon meeting – Saturday 23rd July – 5pm
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 its traditional features with more modern facilities. The Hotel offers a large beer garden which features a lake and its own resident duck family.

Vote for the WPI on facebook

Chase International recently created the Chase Community Giving program enabling participants to determine which small US non-profit organisations will receive donations of more than $5 million from Chase's philanthropy funds. The top 100 eligible organizations with the most votes earn $25,000 during Round One. During Round Two, the top eligible charity earns $500,000 and the remaining 99 earn anywhere from $20,000 to $400,000.

CHASE
COMMUNITY GIVING
you decide what matters

It is up to us to garner enough votes so that WPI (Whittemore Peterson Institute) can be one of the winning organisations. On or about May 5, 2011, the votes will be tallied.

Winning a portion of these funds will help WPI further its mission to bring discovery, knowledge, and effective treatments to patients with neuro-immune diseases.

Please log on to Chase Community Giving at…
http://apps.facebook.com/chasecommunitygiving/charities/205904991-whittemore-peterson-institute

…and cast your vote.

New spinal fluid analysis distinguishes lyme disease from ME/CFS and both from healthy controls

February 23, 2011
Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15959

New tests suggest the central nervous system is involved in ME/CFS and Lyme, and that protein abnormalities in the CNS “are causes and/or effects of both conditions.” [Note: this news made headlines around the world, but was highlighted first Feb 23 on "The CBS Evening News with Katie Couric" - with the headline "Chronic fatigue syndrome - new scientific evidence that it's not in the mind of the patient but very real."]

Patients who suffer from Neurologic Post Treatment Lyme disease (nPTLS) and those with Chronic Fatigue Syndrome report similar symptoms. However, unique proteins discovered in spinal fluid can distinguish those two groups from one another and also from people in normal health, according to new research conducted by a team led by Steven E. Schutzer, MD, at the University of Medicine and Dentistry of New Jersey and Richard D. Smith, PhD, at Pacific Northwest National Laboratory.

Their findings, published Feb 23 by the free access journal PLoS ONE (“Distinct Cerebrospinal Fluid Proteomes Differentiate Post-Treatment Lyme Disease from Chronic Fatigue Syndrome”), also suggest that:

- both conditions involve the central nervous system; and
- protein abnormalities in the central nervous system are causes and/or effects of both conditions.

The investigators analyzed spinal fluid from three groups of people. One group consisted of 43 patients who fulfilled the clinical criteria for Chronic Fatigue Syndrome (CFS). The second group consisted of 25 patients who had been diagnosed with, and treated for, Lyme disease but did not completely recover. The third group consisted of 11 healthy control subjects.

“Spinal fluid is like a liquid window to the brain,” says Dr. Schutzer.

By studying the spinal fluid, the research team hoped to find abnormalities that could be used as markers of each condition and could lead to improvements in diagnosis and treatment.

Taking advantage of previously unavailable methods for detailed analysis of spinal fluid, the investigators analyzed the fluid by means of high powered mass spectrometry and special protein separation techniques.

They found that each group had more than 2,500 detectable proteins. The research team discovered:

1. 738 proteins that were identified only in CFS but not in either healthy normal controls or patients with nPTLS; and
2. 692 proteins found only in the nPTLS patients.

Previously there had been no available candidate biomarkers to distinguish between the two syndromes, nor even strong evidence that the central nervous system is involved in those conditions.

This research represents the most comprehensive analysis of the complete spinal fluid proteome (collection of proteins) to date for both Chronic Fatigue Syndrome and Neurologic Post Treatment Lyme disease (nPTLS).

Prior to this study, many scientists believed that CFS was an umbrella category that included nPTLS. However, these results call those previous suppositions into question.

According to Dr. Schutzer, spinal fluid proteins can likely be used as a marker of disease, and this study provides a starting point for research in that area.

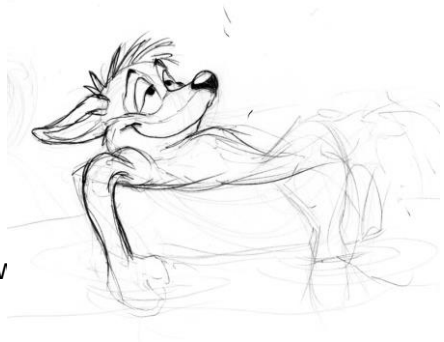
“One next step will be to find the best biomarkers that will give conclusive diagnostic results,” he says.

“In addition, if a protein pathway is found to influence either disease, scientists could then develop treatments to target that particular pathway.”

“Newer techniques that are being developed by the team will allow researchers to dig even deeper and get more information for these and other neurologic diseases, says Dr. Smith.

"These exciting findings are the tip of our research iceberg.”

The ten commandments for reducing stress



1. Thou shalt not be perfect or try to be.
2. Thou shalt not try to be all things to all people.
3. Thou shalt leave things undone that ought to be done.
4. Thou shalt not spread thyself too thin.
5. Thou shalt learn to say "NO."
6. Thou shalt schedule time for thyself, and for thy supporting netv
7. Thou shalt switch off and do nothing regularly.
8. Thou shalt be boring, untidy, inelegant and unattractive at times.
9. Thou shalt not even feel guilty.
10. Thou shalt not be thine own worst enemy, but thine own best friend.

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=14450

ME awareness month

May is the International ME Awareness Month - a world event to raise awareness of ME. The overview below is from the Invest in ME website.

Misinformation
ME is a neurological illness.

For decades there has been a coordinated policy of misinformation about ME presented by vested interests. ME is a neurological illness accepted as such by the UK government as directed by the World Health Organisation.

Ireland is the latest country to ban ME patients from donating blood - the reason being

"to protect blood recipients (i.e. patients who receive blood)"

Why would this be necessary unless ME were of an infectious origin?

(USA, Canada, Australia, New Zealand, Malta, Norway and the UK have also banned blood donations from people with ME)

Medical ignorance
Too little professional awareness, too much trust in establishment organisations such as NICE and the MRC, lack of funding of proper research - all of these contribute to medical ignorance.

This ignorance so often pervades the NHS. However, things are changing slowly. Aided by the biomedical research which has been presented at conferences such as those organised by Invest in ME and its European ME Alliance partners the level of knowledge about ME is growing. Biomedical research has proven beyond doubt that there is a viral origin for most ME patients.

This education will continue.

- Over 60 outbreaks of ME have been recorded worldwide since 1934
- ME is 3 times more prevalent than HIV/AIDS – twice as prevalent as MS
- 25% of ME patients are severely affected - housebound, bedbound
- 25,000 patients are children
- ME is the largest cause of long term sickness absence from school for pupils and staff

Misdiagnosis
Misdiagnosis is one of the most sinister consequences of a healthcare system which is based on lack of funding for biomedical research and which attributes all unknown conditions to a waste-bin diagnosis.

Discrimination
ME patients are dealt a double blow. Not only do they have to deal with the effects of a neurological illness - they also have endure the discrimination which is given to patients by healthcare providers, social services and the DWP. Although the UK government officially recognises ME as a neurological illness it allows the disease to be treated as though it does not exist.

No Funding of Biomedical Research Since IiME was founded we have been campaigning for a national and international strategy of biomedical research into ME.

ME patients have no approved drugs for treatment

ME patients have no access to specialist ME consultants

ME does not discriminate, anyone can be affected

Government apathy
Each successive government of recent years could have acted on the need for more research, for removal of vested interests from decision-making related to ME, for proper attention to education for children with ME, for human rights, ...etc

The attitudes of successive ministers of health has, up to now, been negligent.

The Chief Medical Officers of England have declined to attend every one of Invest in ME's international ME/CFS conferences which take place every year just a few hundred metres from the CMO's office.

The government and the CMO can change this - yet they continue to do nothing.

Isolation
Many people with ME will experience the isolation that comes with ME.

Most parents will see the awful consequence of this disease as it plays out its effect on their child/children.

This is one of the cruellest consequences of a disease which receives no attention, no funding of biomedical research, no interest from the healthcare providers, no policy from the government and no sensible or informed reporting from the media.

A brain MRI study of chronic fatigue syndrome: evidence of brainstem dysfunction and altered homeostasis

by Leighton R Barnden, Richard Kwiatek, et al.
March 2, 2011

[Note: This is a preview abstract in advance of publication, posted Mar 1 by ME/CFS Australia (http://sacfs.asn.au).

To explore brain involvement in chronic fatigue syndrome (CFS), we have extended statistical parametric mapping of brain magnetic resonance (MR) images to whole-brain voxel-based regressions against clinical scores. Using SPM5 we performed voxel-based morphometry (VBM) and analysed T1- and T2-weighted spin-echo MR signal levels in 25 CFS subjects and 25 normal controls (NC).

Clinical scores included CFS fatigue duration, a score based on the 10 most common CFS symptoms, the Bell score, HADS anxiety and depression, and hemodynamic [blood flow] parameters from 24 hour blood pressure monitoring.

We also performed group × hemodynamic score interaction regressions to detect locations where magnetic resonance regressions were opposite for CFS and normal controls, thereby indicating abnormality in the CFS group.

In the midbrain, white matter volume was observed to decrease with increasing fatigue duration.

For T1-weighted MR and white matter volume, group × hemodynamic score interactions were detected in the brainstem (strongest in midbrain grey matter), deep prefrontal white matter, the caudal basal pons and hypothalamus.

A strong correlation in CFS between brainstem grey matter volume and pulse pressure suggested impaired cerebrovascular autoregulation. [Regulation of blood flow in the brain.]

We argue that at least some of these changes could arise from astrocyte dysfunction. [Astrocytes are important star shaped ‘glial’ cells in the grey matter that play a number of roles including support of nerve-cell communications - and quality of memory formation, according to a study published Mar 4, 2011 by the journal Cell.]

These results are consistent with an insult to the midbrain at fatigue onset that affects multiple feedback control loops to suppress cerebral motor and cognitive activity and disrupt local central nervous system homeostasis, including resetting of some elements of the autonomic nervous system.

Source: NMR in Biomedicine [preview], Mar 1, 2011. Barnden LR, Crouch B, Kwiatek Rr, Burnet R, Mernone A, Chryssidis S, Scroop g, Del Fante P.

Initial statement on the PACE trials

By Invest in ME, February 2011

The PACE Trials have recently been published and demonstrate clearly what is wrong with the present way that vested interests have manipulated the establishment view about myalgic encephalomyelitis (ME/CFS) and forced tens of thousands of patients and their families to live in a continual state where no proper research is sanctioned, good science is denied and where pointless and biased studies are funded by a system which denies human rights.

Simple facts:

The Pace Trials cost nearly £5 million pounds of tax payers' money.

Patients were opposed to the trials right from the start due to patient selection criteria - save from two unrepresentative organisations who have taken money from the government in order to accept their policies toward ME.

ME is a distinct neurological illness and has been classified as such since the 1969 by the WHO in ICD10-G93.3. Fatigue Syndrome has its own classification in F48.

It is in none of the patient groups' interest in mixing these patient cohorts and trying to find a one size fits all management technique.

The purpose of any medical research should be the benefit of the patients and the PACE trials do not benefit ME patients but rather known vested interests who control what the media publish and what the Medical Research Council fund in relation to ME/CFS.

In recent years Invest in ME has been contacted more and more by patients or their carers asking for advice as the NICE guidelines recommendation of using CBT and GET has been forced upon them and patients have been bullied into activities beyond their limits.

This has led to some severe consequences such as suicide attempts but parents of children in such cases are often afraid of complaining due to fear of their children being taken into care.

We fear this is going to get worse now after these PACE trial results are being taken at face value.

How ironic it is that the Department of Health and the UK National Blood Services permanently prohibit people with ME/CFS from donating blood - their reasoning being that ME/CFS is a relapsing condition and this was to protect the health of patients. Yet now the message to the healthcare professionals from the PACE trials is that graded excercise and cognitive behaviour therapy are helpful - thus forcing vulnerable and physically ill people to risk further damage to their health.

By any measure the PACE trials are flawed and are not the result of proper research. Using diagnostic criteria which do not define patients with ME/CFS and which exclude people with neurological disorders means that patients participating in these trials were of a heterogeneous variety – thus making the results completely irrelevant. This nullifies all of this study.

The PACE trials are designed, created and performed by those who view ME/CFS as a consequence of wrong illness beliefs or deconditioning.

The PACE trials are bogus science and have no relevance in the treatment of people suffering from myalgic encephalomyelitis.

UK PACE trials: when misguided doctors can do more harm than good

by Whittemore Peterson Institute, March 2, 2011

Cognitive Behavioral Therapy, (CBT) and Graded Exercise Therapy (GET) were developed as support therapies for those with primary depression who are otherwise in good health.

It is well known that appropriately diagnosed M.E. and CFS patients suffer from physical infectious symptoms including sore throat, lymphadenopathy, low grade fever, night sweats and other flu like symptoms which would make it irrational to even suggest the use of CBT or GET as actual treatments.

Just as doctors would never prescribe such treatments for strep throat or Hepatitis C it is irresponsible to suggest these methods would be effective for patients with ME and CFS. In addition, research physiologists have shown that patients suffer from relapses of their illness when forced to exercise against their will or when told to “push through” their illness.

Since the WPI’s discovery of the high correlation of a retroviral infection, with those who suffer from neuro-immune diseases, it is even more important that physicians do not harm their patients psychologically by suggesting they are responsible for, or can be talked out of, their illness.

[Source: Whittemore Peterson Institute for Neuro-Immune Disease, public statement, Mar 1, 2011. http://www.wpinstitute.org/news/news_current.html]

Public misconception about ME/CFS

The following article is an exert from a blog (personal website) of a twenty something male in Adelade Australia. In this exert, he discusses the public confusion between common fatigue and severe ME/CFS.

I am trying to convey how serious CFS can be as there is a misconception in the community about what Chronic Fatigue Syndrome actually is.

The term ‘Chronic Fatigue Syndrome’ is a misnomer. Although post exertional malaise is normally considered a necessary condition to have CFS, it is not a sufficient condition. Also fatigue is normally considered a necessary condition however is not a sufficient condition. From my point of view based on my extensive list of symptoms, my illness is essentially ‘chronic a+b+c+d…..+y+z syndrome’ (with each letter indicating a symptom.) Fatigue for me is just another arbitrary symptom.

Recently on the Dr Oz show in the USA, Dr Oz polled the audience, asking who was exhausted. Keep in mind, the audience were just normal, healthy people. 100% of the audience stated that they were exhausted. In the next poll, Dr Oz polled the same audience and asked who was ‘chronically exhausted.’ 30% of the audience put up their hands. I believe this is indicative of society’s perception of what Chronic Fatigue Syndrome is. This blog will attempt to show that run-of-the-mill ‘chronic exhaustion’ is NOT chronic fatigue syndrome. CFS is a serious debilitating disease and the general public don’t understand at all how serious it is.

These are some quotes indicating how serious CFS is.

“The people with Chronic Fatigue Syndrome are in fact profoundly ill. They are as disabled as anyone with AIDS, with breast cancer, with coronary artery disease.”

William Reeves from the CDC

“I split my clinical time between the two illnesses (CFS and HIV), and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have H.I.V.”

Dr Kilimas

”ME/CFS is actually more debilitating than most other Medical problems in the world, including Patients undergoing Chemotherapy and HIV Patients (until about two weeks before death.)”

Canadian ME/CFS Consensus

“I have treated more than 2500 AIDS and CFS patients over the past 12 years and my CFS patients are MORE sick and MORE disabled, every single day, than my AIDS patients are, except in the last two weeks of life!”

Dr. Marc Loveless

“Research has shown that M.E. has been found to be more disabling than MS, heart disease, virtually all types of cancer, patients undergoing chemotherapy or haemodialysis. It is comparable to end-stage AIDS, i.e. to how ill and disabled an AIDS patient is 2 weeks before death.”

Hooper and Marshall

“CAN you imagine not sleeping for 48 hours, then running a marathon with a hangover and a dose of flu? That’s how it can feel to have ME.”

Ceri Isfryn

“My son has said that he would rather have a disease like cancer or diabetes that is not only treatable, but that people can understand….. I felt like a horrible mother for “wishing” that they would find “a nice simple brain tumor” when they did his MRI of the brain.”

Dr Donnica

“I have had CFS for 25 years and am an 18-year survivor of bilateral breast cancer. To date, the CFS has been far more devastating and disabling than the cancer. Recently, our 32 year-old daughter was diagnosed with early stage breast cancer. Certainly, it was a blow to her and our family to discover she had a cancer in her body which could kill her. But I kept thinking. It could have been worse. She could have been diagnosed with a full-blown case of life-altering CFS, which could have affected her for the rest of her life. That would have been a fate worse than death for our high-energy, adventuresome, life-loving, and hard-working daughter. I mention the above because CFS is considered a “lesser” illness than breast cancer. Breast cancer certainly can kill you and CFS does not normally lead to death. But based on my experience with the two illnesses, I would choose for my daughter to take her chances with breast cancer rather than have to endure CFS.”

Anonymous presentation to the CFSAC

”You talk to CFS patients and they say, ‘Thank God I have a deadly retrovirus’, thank you.”

Judy Mikovits referring to XMRV being a possible cause of CFS.

“Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.”

http://www.ahummingbirdsguide.com/

Article source: http://livingwithchronicfatiguesyndrome.wordpress.com/2009/11/16/how-severe-cfs-is/