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AONM Newsletter June 2014

ME and beyond: Lyme testing



The Academy held a talk for the Colchester ME Self-Help group on May 3. A large audience of around 40 people attended. Professor Basant Puri spoke about the importance of slow-wave sleep in ME, why it is so

hard to reach that particular sleep state in the illness, and methods to restore regenerative sleep. The second topic he covered was the overlap between Lyme Disease and ME – the former often being misdiagnosed as the latter. He explained that taking a thorough case history is the key, and that careful testing is essential if there is even a hint of suspicion that Lyme could be involved.

Gilian went on to discuss testing for Lyme Disease and coinfections. She explained the vagaries of Lyme testing, looking first at NHS testing, and then private testing options.

Tests available on the NHS

"All commercial Borrelia diagnostic tests are based on one or two laboratory strains and therefore their sensitivity is poor. If these tests were based on clinical specimens then we would not miss as many cases." - Dr. Joseph Burrascano

All Lyme testing on the NHS is now done at the Rare and Imported Pathogens Laboratory at Porton Down

in Salisbury, having been transferred there from the Health Protection Agency in 2012. There are questions though over the recognition of chronic Lyme Disease as a valid illness in the UK: it is hard to get permission for a Lyme test if you cannot provide evidence of a recent bite. Generally the first test done is an ELISA - an enzyme-linked immunosorbent assay. RIPL uses the C6 ELISA: this detects a synthetic peptide that is a component of the VIsE envelope antigen – an outer surface lipoprotein on the spirochetes of B burgdorferi. The problem is that spirochetes are masters at evading the immune system, so this surface protein constantly changes at least 15 variants exist. This ability to evade the test marker means the ELISA test is insufficiently sensitive, and misses over 50% of cases according to many experts in the field.

The Western blot (WB) is traditionally the second stage of testing. Its gel electrophoresis technique uses more indicators than an ELISA. The sensitivity of a WB is said to be around 60%, so higher than an ELISA, but still by no means infallible.

Private testing

Infectolab is a large German laboratory that has specialised in Lyme testing for many years (there has traditionally been a lot more recognition of Lyme disease in Germany due to its prevalence in the Black Forest, for example). Infectolab recommends not doing ELISA at all, instead conducting three tests as a standard. One is a WB (they use a EUROLINE RN-AT Immunoblot said to have a high degree of accuracy). An LTT (lymphocyte transformation test) is the second: this tests the current degree of disease activity using isolated lymphocytes from a blood sample and determining the response to specific antigens. Third is a CD57 count. A low count has been correlated with chronic Lyme Disease symptoms. Infectolab claims that doing these together produces a sensitivity of 90%.

PCR (polymerase chain reaction) tests are also used, which measure the presence of DNA. However, these produce many false negatives because Lyme bacteria are sparse in the bloodstream.

There are also multiple coinfections that may be present, and extensive tests for these are also available – at RIPL, too. The difficulty as before is providing sufficient evidence that such an infection may be present. Infectolab has a checklist that the therapist can use to home in on which coinfections are most likely, to rein in the costs of testing.

See the AONM website ("Expertise") for Gilian's Powerpoint slides.

Read the Odyssey of Sarah Mills on <u>http://seatafund.wordpress.com/sarah/</u>, who was diagnosed with ME for many years. It was 17 lost years before her condition was finally recognised as Lyme.

It's mitochondria, not hypochondria



Dr Sarah Myhill's new book "Diagnosis and treatment of Chronic Fatigue Syndrome -It's mitochondria, not hypochondria" throws spotlight the on ME/CFS as a symptom of mitochondrial failure. The two symptoms Dr. Myhill looks for to make a diagnosis are poor

stamina and delayed fatigue. She describes the mitochondrial function score – the tests she has been using for many years now to calculate a patient

"energy score", using tests from ACUMEN, the advanced mitochondrial laboratory in Devon.

The book also provides a very helpful description of other tests run by ACUMEN, which are otherwise relatively unknown, such as "Microrespirometry", looks which more closely at oxidative phosphorylation and indicates where in the electron transport chain a breakdown may have occurred, whether due to substrate inefficiency or a chemical inhibitor. "Mitochondrial membrane TL (translocator protein) studies" shows what chemical or heavy metal is bound to the mitochondrial membrane, the pH of the outer mitochondrial membrane (reflecting intracellular pH), and any lipid peroxidation. (A variety of further unique tests are described from pages 38 - 60.)

Several studies have been conducted using ACUMEN's "CFS profile" and the mitochondrial function score derived from this. They found that the ATP production in patients suffering from ME/CFS is closely correlated with illness severity, clearly demonstrating that "these patients have serious biochemical pathology. They do not suffer from hypochondria – the problem is their mitochondria." Dr. Myhill then goes on to describe the techniques she uses to elevate ATP production. She builds a treatment programme based on what she calls her "basic work-up for all CFS sufferers." This is a tailored therapy involving eating an evolutionarily "Stone Age" diet, taking targeted correct micronutrients and introducing the right pacing and sleep hygiene.

From organophosphate poisoning to phospholipid exchange to EPD (Enzyme-Potentiated Desensitisation), this book is a treasure trove of highly useful information. It is a must, whether for laypeople or therapists attempting to get a handle on the elusive diagnosis of ME/CFS.

Diagnosis and treatment of Chronic Fatigue Syndrome – It's mitochondria, not hypochondria, Dr. Sarah Myhill, Hammersmith Health Books 2014

The Glymphatic System

Neuroscientists at the University of Rochester Medical Center around JJ Iliff have discovered a previously unrecognized system that drains waste from the brain. The new system has been termed "the glymphatic system" because it has a similar action to the lymphatic system, but is managed by the brain's glial cells. This system drains away waste products. "Waste clearance is of central importance to every organ" says Maiken Nedergaard MD, DMSc, senior author of the paper. "This work shows that the brain is cleansing itself in a more organized way and on a much larger scale than has been realized previously."



An artery in the brain of a mouse. The green shows cerebrospinal fluid in a channel along the outside of the artery

The team are hoping that their findings will have implications for multiple brain-related conditions such as Alzheimer's and Parkinson's disease. The Academy works closely with Dr. Ray Perrin ("The Perrin Technique for ME/CFS"), who has been investigating the involvement of cerebrospinal fluid and lymphatic drainage in CFS/ME for many years. AONM is also dedicated to pursuing structural approaches to conditions like fibromyalgia and ME, and has outstanding osteopaths in its network/at its clinic, such as Marcia Harewood and Dr. Harald Gaier.

Please contact AONM if you would like a DVD on the PC3 technique we reported on in our May newsletter – positional cervical cord compression, a field pioneered by the rheumatologist Dr. Andrew Holman.

"A Paravascular Pathway Facilitates CSF Flow Through the Brain Parenchyma and the Clearance of Interstitial Solutes, Including Amyloidβ"

http://stm.sciencemag.org/content/4/147/147ra111

EMF mechanism of action finally explained

How do electromagnetic fields – fields of low-impact photons – influence our biology? The mechanism has not previously been explained.



Professor Martin Pall was over in the UK in March 2014 at the BSEM's (British Society of Ecological Medicine, http://www.bsem.org.uk/) first conference of the year on Electromagnetic Radiation and Health, and spoke on EMFs, intracellular calcium imbalance and the NO cycle.

He presented the findings from his new paper "Electromagnetic fields act via activation of voltagegated calcium channels to produce beneficial or adverse effects." This paper reviews 24 different studies showing that EMF exposures act by partially depolarizing the electrical charge across the plasma membrane of cells, activating the voltage-gated calcium channels in our cell membranes. It is the increased intracellular calcium levels that are responsible for the reaction to EMF exposure.

These studies implicate VGCCs in responses to a variety of EMFs, including those produced by alternating currents in our wiring, various microwave/radio frequency EMFs and nanosecond electrical pulses. Telling patients to remove all sources of EMFs from their environment – at least at night, switching off routers, smartphones, iPads, etc – has much more weight now that it is linked to a precise biomedical mechanism.

http://onlinelibrary.wiley.com/doi/10.1111/jcmm.12 088/pdf

Martin Pall, PhD Professor Emeritus of Biochemistry and Basic Medical Sciences, Washington State University



Corporate Wellness

This month's BIG 'NO-NO': Microwaving food in plastic containers

As you open the microwave to pull out your piping hot lunch, you congratulate yourself on the healthy choice you've made. Or have you really?

A quick online search reveals 'heated' controversy around the dangers of plastic chemicals in food. According to some, the idea that plastic in our bodies constitutes a health risk is nothing but a hoax, but ever more evidence is emerging. Recently the FDA announced a reversal of its 2008 claims regarding the safety of Bisphenol-A (one of the most common components of plastic), expressing new concern about "potential effects of BPA on the brain, behaviour and prostate gland of foetuses, infants and children."¹

And it's not just BPA, there are other chemical compounds in plastic that are very likely to leach out of plastic into food, especially when heated. The US-based National Institute of Environmental Health Sciences advises against microwaving polycarbonate plastics or putting them in the dishwasher because the plastic may break down over time and allow BPA to leach into foods.² The health risks experts are talking about are linked to hormone disruptions, brain and behavioural problems, cancer, cardiac issues and obesity.

While we await more scientific research into the matter, one thing is certain: most of us already have BPA in our bodies according to research carried out by the Center for Disease Control and Prevention.³

Are you prepared to take the risk? If you have no choice but to use a microwave, keep a glass bowl or a plate in the kitchen at work to transfer the food into.

References:

¹http://www.sciencedaily.com/releases/2010/03/100 319115631.htm

² <u>http://ehp.niehs.nih.gov/119-a306b/</u>

³<u>http://www.cdc.gov/biomonitoring/BisphenolA_Fa</u> <u>ctSheet.html</u>

Events

Gilian Crowther is speaking at CAM Conferences on Saturday June 7 on **Mitochondrial Detoxification with Cell Symbiosis Therapy**® at Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT; her talk is at 10.00 am:

http://www.camconferences.com/?page_id=385

She is also holding an **Introductory Seminar on Cell Symbiosis Therapy** – a mitochondrial approach to therapy – at the Holiday Inn Bloomsbury, Coram Street, London WC1N 1HT on Saturday June 28, from 10.00 - 5.00 pm. Please contact <u>gilian@aonm.org</u> to register, or call 0786 772 6387. There is also an Eventbrite site on which you can sign up:

<u>https://www.eventbrite.co.uk/e/cell-symbiosis-</u> therapy-introductory-seminar-with-gilian-crowtherregistration-11792602993 (the link to this is on the www.aonm.org/events page).

The fee is £35 for earlybird registration before June 12, and £45 for later. Members of AONM and the NNA receive a discount of £5.

If you use the ACUMEN tests and would like to deepen your knowledge of them, please email <u>info@aonm.org</u>, as we will also be holding a small event on those specialist tests.

Please contact us at any time if you are interested in learning more about our services, or exploring how we could work together: <u>info@aonm.org</u>/0845 505 1296, or go to www.aonm.org

