

Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Spring 2010

Future dates

Morning meet – Monday 21st June – 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 meet – Tuesday 13th July – 6pm

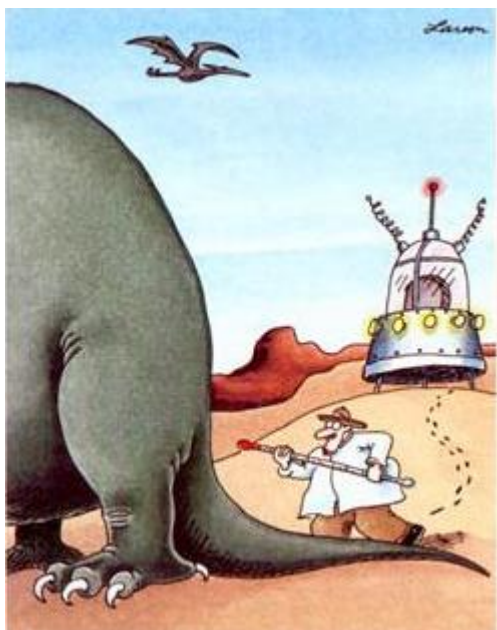
Worplesdon Place Hotel, Perry Hill, Worplesdon, Guildford, Surrey, GU3 3RY

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.

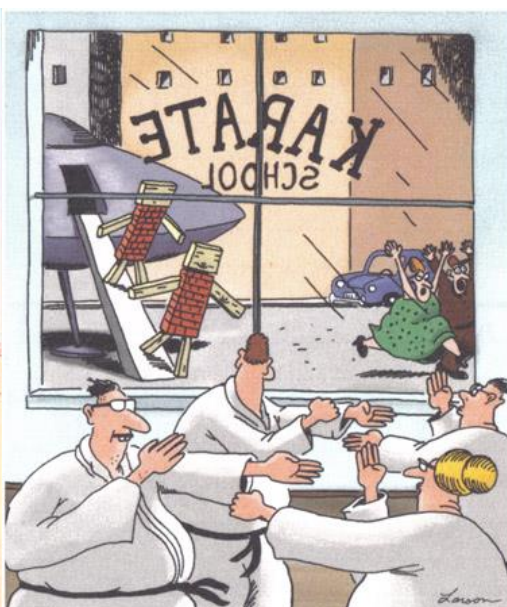
Afternoon meet – Thursday 5th August – 3pm

The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU.

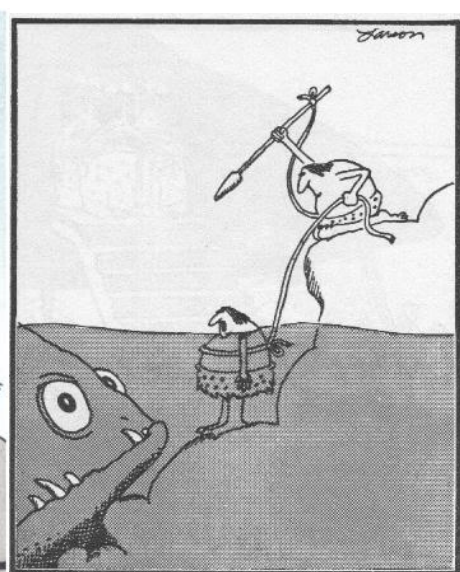
Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham). Food available includes: wood fired pizzas, spit roast chickens, plenty of fresh fish and the finest steaks.



An instant later, both Professor Waxman, and his time machine are obliterated, leaving the cold-blooded / warm-blooded dinosaur debate still unresolved



The class abruptly stopped practicing. Here was a chance to not only employ their skills, but also to save the entire town



"Now, Grog! Throw! Throooooooooow.... Throw throw throw throw throw..."

Beneficial nutritional supplements to support XMRV patients

February 26, 2010

Source: <http://www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15181>

During the Q & A period following her recent XMRV presentation sponsored by the HHV-6 Foundation and ProHealth, Whittemore Peterson Institute Research Director Dr. Judy Mikovits, PhD, was asked what kind of therapies those who tested positive for the XMRV retrovirus could try until specific drug or other treatments are developed.

Although Dr. Mikovits was quick to note that she is not a physician, she mentioned five areas of concern for people with XMRV and suggested that nutritional supplementation to strengthen those areas could be helpful.

Based on her insights, ProHealth suggests a number of options known to be helpful for these concerns, as outlined below. Please note, however, that Dr. Mikovits has made no specific product recommendations, nor does she endorse these products in any way.

1. Decrease inflammation

In her presentation, Dr. Mikovits said, "...we know that CFS is a multi system disorder but there's lots of inflammation going on – you have allergies, multiple chemical sensitivities. There's a lot of inflammation and increased numbers of activated T cells and the production of these inflammatory molecules I mentioned known as cytokines and kinokines."

When it comes to decreasing inflammation, there are two options: drugs and supplements. The drugs that help reduce inflammation are non-steroidal anti-inflammatories, both over-the-counter and prescription. In terms of supplements, below are five good anti-inflammatory options to consider:

- Vitamin D – Vitamin D is known to play an important role in supporting the body's defenses against inflammatory diseases. In a 2008 study, increased concentrations of the inflammatory marker serum tumor necrosis factor-alpha were linked to a vitamin D deficiency in healthy women.(1) The findings from this study indicate that low vitamin D has a negative impact on inflammation and immune response.
- Curcumin – The use of curcumin to help the body fight inflammation dates back to ancient India where it was commonly used in Ayurvedic holistic medicine. In more recent times, researchers around the world have documented what one research team described as curcumin's "remarkable anticarcinogenic, anti-inflammatory, and antioxidant properties."(2)
- Zyflamend – Zyflamend™ is a supplement blend containing 10 herbs which are known for their ability to promote a healthy inflammation response: rosemary, tumeric (cucumin), ginger, holy basil, green tea, hu zhang, Chinese goldthread, bayberry, oregano, and baikal skullcap. One of the ingredients, holy basil, is also an antioxidant and supports healthy cortisol levels, which are two additional areas Dr. Mikovits recommends strengthening.
- Proenzyme P – ProEnzyme P™ helps support the inflammation response system by utilizing systemic oral enzymes. These enzymes hasten the inflammation process to promote healthy tissue function. ProEnzyme P™ supports the inflammation response by helping the body to break up large pro-inflammatory immune complexes that have accumulated in the body.
- FibroFreedom – The FibroFreedom™ formula contains four ingredients that promote a healthy inflammation response: white willow bark, MSM, boswellin, and curcumin – as well as five additional nutrients that can help with other common symptoms of fibromyalgia and ME/CFS.

2. Reduce oxidative stress

According to Dr. Mikovits, "Supplements [i.e., antioxidants] can help a lot because retroviruses cause a lot of oxidative stress.... Things like N-acetyl cysteine and glutathione (the detox type)."

We hear a lot about antioxidants these days because they are the body's natural defense system against harmful free radicals and are essential for overall good health. There are dozens of antioxidant products, like grapeseed and green tea extracts, on the market to choose from.

Some particularly good antioxidant options to consider include:

- Ultra Antioxidant – This is a combination of vitamins, herbs, and extracts that support the body in its fight against harmful free radicals. Ultra Antioxidant™ contains vitamin A (beta-carotene), Ester C®, and vitamin E – plus 12 other ingredients including alpha lipoic acid, green tea extract, grapeseed extract, N-acetylcysteine and L-glutathione, which all help to protect against free radical damage.
- Reduced L-Glutathione – Glutathione has been called the “master antioxidant” because it enables all other antioxidants to achieve their maximum benefit. It protects the body by targeting and destroying reactive oxygen molecules and free radicals. Glutathione also flushes away toxins, supports cell health and integrity, and strengthens immune system activity.
- N-acetyl cysteine (NAC) – N-acetyl cysteine is a potent antioxidant and cell detoxifier that is derived from the amino acid L-Cysteine. Its primary function is to enhance the production of glutathione.
- Alpha Lipoic Acid – Alpha Lipoic Acid, an antioxidant in its own right, also enhances glutathione levels as well as supporting the action of other antioxidants. In his review of research on alpha lipoic acid in the journal *Free Radical Biology & Medicine*, Lester Packer, MD, PhD, writes that alpha lipoic acid acts as an antioxidant “not only directly, through radical quenching and metal chelation, but indirectly as well, through recycling of other antioxidants and through the induction of increased intracellular levels of glutathione.”(3)
- ImmunoPro RX or ImmunPlex – Both of these products contain whey protein, which has exceptional amounts of cysteine and glutamine, the precursors required for the production of intracellular glutathione. Regarding whey protein concentrate, the journal *Immunology* reports, “The bioactivity occurs through the ability of the protein concentrate to help replenish Glutathione levels via continuous dietary provision of Glutathione precursors, especially Cysteine, during lymphocyte proliferation, thus supporting an optimal immune response. This process seems to not only increase intercellular levels of Glutathione and precursors at the time of ingestion, but also builds up stores of these substances within the cells that lasts for a substantial post-ingestion time interval.”(4)

3. Upregulate natural killer cell function

Natural Killer cells are an important part of the immune system. They are lymphocytes circulating in the blood whose purpose is to kill certain types of target cells – particularly cancer cells and cells that have been infected with a virus. New research has revealed that Natural Killer cells also play a role in keeping T cells – another major player in the immune system – from over-responding and causing harm.(5)

Dr. Mikovits explained the part Natural Killer cells play in the pathogenesis of ME/CFS, “A key dysfunction in the immune system of CFS patients is this low Natural Killer cell activity and sometimes numbers. The Natural Killer cell has two jobs in the body – kill tumor cells and kill virus-infected cells. In CFS it's long been recognized (I think first identified by Nancy Klimas and her colleagues more than 20 years ago) that Natural Killer cells in CFS patients don't function normally although the dysfunction is not known, but that again gives us a clue to the pathogenesis. So this suggested to us that this chronic infection with a retrovirus (retroviruses are associated with immune deficiencies) might lead to the creation of actual immune deficiency that has patients susceptible to opportunistic infections and more likely to develop cancer.”

A number of different studies have confirmed irregularities of the immune systems of ME/CFS patients – sometimes it is over-reactive and other times it is under-reactive. Since we now know that Natural Killer cells can actually help control both, it appears that upregulating the function of natural killer cells should have a positive effect on helping to improve the immune system for people with ME/CFS.

Three supplements that can be beneficial in upregulating Natural Killer cell function are:

- EpiCor Immune Complex – EpiCor® is a yeast-based immunogen that in a 2007 study was shown to activate Natural Killer cells.(6) Another study done a year later found that two hours after the consumption of EpiCor, the number of Natural Killer cells had doubled.(7) In addition to its support of the immune system, EpiCor is also a powerful antioxidant.
- Transfer Factor Essentials – Transfer factors are tiny protein molecules produced by the T-cells of the immune system. Transfer Factor Essentials™ offers a complex blend of transfer factors plus vitamins and nutrients called Matrix 2000™ that works to stimulate and strengthen Natural Killer cells.

- AHCC with Beta Glucan – AHCC with Beta Glucan™ is an immune enhancing combination of AHCC (a proprietary blend of mushrooms that helps increase immune-regulating cells) and beta glucan, a potent yeast extract. Beta glucan boosts immune system cells including Natural Killer cells, macrophages, and neutrophils - which provide the immune system's first line of defense, help remove cellular debris, and support recovery of damaged tissue.

4. Monitor and possibly reduce hormone levels

Thus far, only three things have been found that turn on the XMRV virus. Dr. Mikovits explained, "Two are called glucocorticoid response elements... When a protein actually recognizes that exact sequence and sits down, it tells the virus to turn on replication. And so, interestingly enough, what turns on the virus? Hormones – progesterone, androgen receptor and testosterone, and we don't know all the other hormones. There are a lot of estrogens and estrogen like compounds even in our environment these days, which might tell us maybe there's an estrogen compound that's not a naturally occurring estrogen in a plastic in the environment that is actually turning on the virus."

As for what to do regarding hormones, she said, "I don't know much about hormone therapies and how lowering hormone levels might help, but I do know anecdotally that a lot of women in a particular time in their cycle get much, much sicker and can't get over it. I do know in the laboratory, progesterone really upregulates the virus, so if you have a birth control pill... and again I don't really know anything about this... I'm not a physician... you might think about just keeping the levels balanced and avoiding the fluctuation."

The implication is that you might want to avoid anything containing progesterone or other hormone-related products, rethink the birth control pill, and maybe avoid pregnenolone, which is a precursor to progesterone & other hormones.

5. Balance cortisol and reduce stress

The third thing known to turn the virus on is cortisol. Cortisol is a stress hormone that can turn on replication of the virus – like an on/off switch. Therefore, Dr. Mikovits recommends staying out of stressful situations, which of course is easier said than done. Since stress can't be avoided entirely, adding a supplement that aids in stress reduction may be helpful.

Magnesium – The primary supplement that helps the body to deal with stress and thereby balance cortisol is magnesium. In fact, magnesium is often called "the anti-stress mineral" because of its calming effect. Since cortisol and other stress hormones can cause serious magnesium loss, it is important to replace the magnesium in order to support a healthy balance. Magnesium is needed by every cell in the body for more than 300 biochemical reactions, but the body does not store it, so it's important to replenish the body's supply of magnesium daily.

Three ProHealth products that can help balance magnesium include: Magnesium Plus, Natural Calm and Osteo Calm.

In summary

Much research still needs to be done before the possible impact of XMRV on ME/CFS and other neuro-immune illnesses is known and anti-retroviral or other treatments can be developed. In the meantime, Dr. Mikovits feels that addressing these five factors can be helpful.

Note: This information has not been evaluated by the FDA. It is general and is not meant to prevent, diagnose, treat or cure any illness, condition, or disease. It is very important that you make no change in your healthcare plan or health support regimen without researching and discussing it in collaboration with your professional healthcare team.

Who's interest is the GMC serving ?

Source: <http://gaia-health.com/articles201/000243-doc-who-harms-no-one-is-punished-by-gmc-doc-who-killed-can-practice.shtml>
by Heidi Stevenson, 12 May 2010

In typical hubristic fashion, the UK's General Medical Council (GMC) has stripped Dr. Sarah Myhill of many of the functions required to care for her patients, while allowing doctors who have killed patients with sloppiness, lies, and egregious errors to continue in practice. She harmed no one, and no such accusation was made. Not a single patient has complained.

The more I look at this case, the more clear it becomes that Dr. Myhill is being persecuted for holding views outside mainstream corrupt medicine. She is not a full supporter of vaccinations. Pharmaceuticals are not the first thing she considers in treatment. She thinks about what she does, rather than following the party line. Those are unacceptable qualities in modern medicine, and any doctor, no matter how well qualified, can expect to be punished for them.



Doctors who've killed are allowed to continue practice

Dr. Myhill practices conservative medicine. As her website states, her goal is "Empowering you to recover your health".

While she effectively loses her license to practice, the GMC has allowed other doctors who have killed patients to continue. Here are three cases:

- Andrew Hall, who cut through the windpipe of Beryl Walters. He chose to do the surgery using an experimental technique that he'd read about while in the army and had never done before. He did not inform her that he'd be doing it and didn't let her know the risks involved. When it became obvious that Mrs. Walters was not doing well and getting worse, he ignored the complications. Even after tests showed that air was collecting outside her lungs, he refused to seek advice or take any steps to correct the damage. Mrs. Walters died of both the botched experimental surgery and Hall's refusal to take appropriate steps to help her over a month-long period during which she deteriorated, but might have been saved.

Andrew Hall is still practicing.

- Dr. Nigel Heaton and his Kings College surgical team went to India to do a procedure that was not approved by the NHS, a live adult to live adult liver transplant. Rather than waiting for a viable donor, they encouraged the wife of a man with liver disease to donate part of her liver. Apparently, they didn't clarify the risks, but painted a rosy picture, saying that her liver would grow back within two weeks. Instead, she ended up on life support. Her husband died of sepsis two weeks after the transplant.

Neither the wife nor the rest of the family were informed that about 1 in every 100 donors dies. They were also not informed that Heaton and his team were not experienced in live-adult-to-adult liver transplants or that they're more dangerous than adult-to-child transplants.

In spite of having concrete evidence of wrongdoing, as the BBC filmed the procedure, the GMC did not take any action against Heaton. The GMC did not even bother to investigate.

On another occasion, Heaton transplanted a liver into a private patient from a middle eastern state, rather than a British child on the NHS. This runs contrary to NHS rules, which require that NHS patients have the first option on donor organs. In spite of the fury of other doctors, the GMC hasn't even looked at the incident.

- Dr. Jane Barton overdosed patients with opiates. One witness stated that it was to keep them quiet.

At least 12 of her patients died from the treatment, and as many as 100 may have.

The GMC decided that her previous 10 years without a known problem and the support of 200 patients were taken into account in allowing her to continue to practice without limitations, though they found her guilty of serious professional misconduct.

In contrast, more than 800 letters from the patients of Dr. Myhill were considered of no value, and her nearly 30 years of practice without problem were considered irrelevant.

The complaints against Dr. Myhill

Two accusations were made against Dr. Myhill. One was by another GP group, who complained she recommended that a patient be given Vitamin B12 injections to treat chronic fatigue syndrome. This was not a recommendation made to the patient.

The other accusation was made anonymously. He posted on the website, Bad Science, stating that he'd made the current complaint. The level of humor exhibited by the complainant is prepubescent, as exemplified by his comment in his discussions of the issue on Bad Science, "Those who live in glass houses should masturbate in the basement."

Please note the the previous paragraph has been modified to reflect more accurate information. It previously stated that a standup comic had made the accusation. Rather, the complainer had quoted the comic.

Not a single patient has complained about Dr. Myhill's practice. In fact, more than 800 of her patients sent letters to the GMC supporting her. Many of them are fearful at losing her services, as she is the only doctor who has helped them.

Dr. Myhill's punishment for providing patients with genuine help

There is no sense in the restrictions placed on Dr. Myhill's practice. She was criticized for recommending to another GP that Vitamin B12 injections be given to a patient, yet her ability to prescribe anything from the British National Formulary was circumscribed.

It's rather puzzling, but the fact is that no findings against Dr. Myhill were made. Nonetheless, they determined that "it is necessary for the protection of members of the public and in the public interest to make an order imposing...interim conditions on [Dr. Sarah Myhill] for a period of 18 months." These include:

- loss of ability to prescribe any prescription medication.
- removal of several pages of information from her website, including any related to cardiovascular disease, asthma, breast cancer, hormonal contraceptives, pharmacological management of vascular disease, immunization, and vaccination.
- approval of the GMC before accepting any post for which GMC registration is required.
- GMC must be informed if she applies for medical employment outside the UK.
- any potential employer of any sort must be informed of the restrictions made by the GMC.

In effect, Dr. Myhill has lost the ability to practice as a physician—and she is being gagged.

The GMC inquisition's methodology

The GMC gave Dr. Myhill virtually no time to prepare a defense. She was notified only one day before the planned hearing, usually referred to as an Interim Orders Panel (IOP). She asked for an extension, and was given 13 days—though the expert witness's report was given to her only three days before the hearing. The GMC's own rules require that the doctor be given reports at least ten days in advance.

The so-called expert witness was an endocrinologist with no experience in chronic fatigue syndrome or mitochondrial disorders, the conditions that Dr. Myhill has studied and specialized in treating.

Although it's illegal, Dr. Myhill's patients' records were reviewed by the IOP in an obvious attempt to find something—anything—on which she could legitimately be charged. Her patients' rights were violated, and it served no purpose. They found nothing.

It was supposedly a public hearing, but no member of the public was allowed to record it, not even with a tape recorder. The only recording allowed was the official GMC written account. Dr. Myhill learned that 47 letters she'd written to the GMC regarding the previous six failed attempts to shut her down had somehow disappeared. When she complained about it, the response was a stonewall. She wrote to the Information Access Officer, Julian Graves, on 24 February 2010, citing the missing letters and their dates. Such requests are supposed to be answered within 21 days. She received an answer 64 days later—on the date of her IOP hearing: The letters were delivered to her office with a cover letter from Graves, stating, "I am sorry that some of these letters were not disclosed to you as a result of your previous subject access requests."

Dr. Myhill wasn't accused of harming patients or putting them at risk. No patients made any complaints. She had, though, been harrassed by the GMC for years, without any findings against her. So, without any complaints against her, they apparently decided that years of safe practice with satisfied patients were meaningless.

Her patients wanted to demonstrate their support for Dr. Myhill, but even that was circumscribed. They were not allowed to demonstrate outside the hearing, and very few were allowed to be present during it.

The loss of expertise

As the GMC in the UK and state medical boards in the US participate in an inquisition against doctors who think for themselves and put their patients first, other doctors fear to speak out and people in need of medical assistance are unable to get it. Dr. Myhill's patients are devastated. The treatment that they've freely sought—the treatment that has proven safe and effective, while mainstream medicine has been both utterly ineffective and outright dangerous—is being denied to them.

The means for removing access to safe and effective treatment is, effectively, to declare the practitioners as heretics. By taking that approach, no facts need to be demonstrated. No real charges need to be proven or even made. All that's needed for the witch hunt is an accusation. As can be seen in the Sarah Myhill case, any accusation from anyone—even a stand-up comic!—is enough to charge and convict of medical heresy.

Just as women, and a few men, were burned at the stake as witches during the dark and middle ages for their knowledge of health and medical lore, the same thing is happening today. Practitioners of real medicine lose the right to practice. Even the right to give information is attacked. Note that Dr. Myhill is required to remove major sections of her website, though no one has demonstrated that anything on it is invalid.

Even people who do not want alternative medicine should care about what happens to Dr. Myhill. If the powers-that-be have the ability to stop her from practicing, at what point will something near and dear to you be banned?

The methylation cycle

by Dr. Sarah Myhill, www.drmyhill.co.uk

Chronic Fatigue Syndrome is a symptom, not a diagnosis, and the name of the game is to identify the underlying causes. In fatigue syndromes we don't see macro-pathology, we see micro-pathology - that is to say the problems are bio-chemical and occur at the molecular level.

There are several cycles, which I now know to be centrally important in causing fatigue. All these cycles interlink with each other like Olympic rings and getting one cycle going will drive another. The important cycles which I know to be major players include blood sugar wobbles, allergy problems, sleep cycles, mitochondrial function, anti-oxidant status, the NO/OONO cycle, thyroid and adrenal hormones cycles and de-toxification. I am greatly indebted to Rich van Konynenburg for updating me on a new player which interlinks with many of the above, namely the methylation cycle.

The methylation cycle

Rich van Konynenburg's idea is that ineffective methylation is a major cause of fatigue. There are many possible reasons but those that he's identified for which methylation is essential to are:

1. To produce vital molecules such as Co Q-10 and carnitine.
2. To switch on DNA and switch off DNA. This is achieved by activating and deactivating genes by methylation. This is essential for gene expression and protein synthesis. Proteins of course make up the hormones, neurotransmitters, enzymes, immune factors and are fundamental to good health. When viruses attack our bodies, they take over our own DNA in order to replicate themselves. If we can't switch DNA/RNA replication off then we will become more susceptible to viral infection.
3. To produce myelin for the brain and nervous system.
4. To determine the rate of synthesis of glutathione which is essential for detoxification.
5. To determine the rate of synthesis of glutathione which is an essential anti-oxidant as glutathione-peroxidase. Furthermore oxidative stress blocks glutathione synthesis - yet another vicious cycle!
6. To control sulphur metabolism of the body, not just glutathione but also cysteine, taurine and sulphate. This is an important process for detoxification.
7. As part of folic acid metabolism. This also switches on synthesis of new DNA and RNA.
8. For normal immune function. The methylation cycle is essential for cell mediated immune function and blockages here will mean that infections will not be adequately dealt with. I know this clinically because many patients tell me that once they get on to their B12 injections (an essential co-factor for methylation) this seems to protect them from getting infections.

The overall effect here is that if the methylation cycle doesn't work, the immune system mal-functions, the detoxification system mal-functions, our ability to heal and repair is reduced and the anti-oxidant system mal-functions.

Testing for how well the methylation works

We don't have a simple test to see how well the methylation cycle works. What we can do is measure levels of homocysteine and SAMe. If these were raised this would show a blockage in one part of the pathway. Indeed, a raised homocysteine we know to be a major risk factor for arterial disease, almost certainly because this represents blockages in the methylation cycle. However, one could have a normal homocysteine and normal SAMe but blockages elsewhere in the system, which would still impair the ability to methylate. So there is no simple test. *[Additional information about testing is included on page 12]*

How do we go about treating this? Rich van Konynenburg has identified a package of micronutrients specifically to support the methylation cycle. He recommends the activated form of vitamins. These are more expensive than the basic forms, but I think that the idea here is that they are necessary in the short term to get the cycle working and in the longer term they can be dropped off. In addition to the basic three B vitamins Rich van Konynenburg has one or two other additions which you may also like to choose to use, but my initial suggestions would be as follows.

The methylation cycle - which supplements to take to support

[Please read our warning about taking supplements for the methylation cycle on page 11]

In order to get the methylation cycle up and running initially we have to prime the pump with the activated vitamins, but hopefully once the methylation cycle is up and running, it can function on the vitamins in their normal states.

This is the package of supplements to support the methylation cycle. It needs to be taken in addition to everything else! But the package will change with time because as the methylation cycle starts to work again, it will start to stand on its own feet. Everyone's package will be a bit different depending on how poorly their cycle is working. One day we will have the biochemical tests to tailor make each package for each person, but until then I suggest the following regime:

For two months a daily dose of

- Hydroxycobalamin 5,000mcgms daily ("shot O B12")
- Methylcobalamin 1mg sublingually
- Methyltetrahydrofolate 800mg (ActiFolate)
- Pyridoxal 5 phosphate 50mgs twice daily
- Glutathione 250mgs daily
- Phosphatidyl Serine 200mgs one daily (BioCare)

If you are better - fine! If you are worse - it may be the abreaction. If you are unchanged, swap the sublingual B12 for injected B12 ie:

- Daily subcutaneous injections methylcobalamin 1/2ml (this is a bit more expensive than cyanocobalamin). I would prefer people to start with this regime but I know many do not fancy the idea of injections - actually I am a wimp too, but they are easy and almost painless.
- Methyltetrahydrofolate 800mg (ActiFolate)
- Pyridoxal 5 phosphate 50mgs twice daily
- Glutathione 250mgs daily
- Phosphatidyl Serine 200mgs one daily (BioCare)
- Lecithin (phosphatidyl choline) and Phosphatidyl Ethanolamine.

If you are better - fine! If you are worse - it may be the abreaction. If you are unchanged add in:

- Tri-methylglycine (also known as betaine hydrochloride, also used to increase stomach acid so take at meal times and be mindful that it may cause symptoms of acidity - see information on hypochlorhydria).
- S-adenosyl methionine (S-AdoMet) directly as a supplement 400mgs daily

Once you are better

Then the regime can be relaxed. Once you are a good methylator, methyl B12, ActiFolate and glutathione could be tailed off. Injections could be swapped for oral supplements. However, do this slowly - some people need a small supplement long term in order to stay well.

1. Methyltetrahydrofolate 800mg (ActiFolate).
2. Hydroxycobalamin 5000mcgms sublingually (Shot-O-B12), together with Methylcobalamin 1000mcgms sublingually. It may be necessary for some people to have B12 by injection to get the best effect (easy to self inject 1/2ml daily, initially as methylcobalamin then switch to the less expensive cyanocobalamin)
3. Pyridoxyl-5-phosphate 50mgs (this is present in the BioCare multivitamin)
4. Phosphatidyl Serine 200mgs one daily (BioCare) These should be taken in addition to my basic package of supplements, namely multivitamins, Myhill Magic Minerals, essential fatty acids, vitamins C and D - these are the supplements I like all people to take on a regular basis.

The remainder of this article can be found at:

<http://www.ei-resource.org/articles/chronic-fatigue-syndrome-articles/the-methylation-cycle/>

IMPORTANT NOTICE: Please, note that Dr Konynenburg is a researcher and not a medical doctor and that he does not give advice about treatment for individual cases independently of their physicians.

The methylation cycle – treatment warning

The following information was provided by a new group member, Will Marsden.

The methylation cycle controls some of the most important detoxification and immunity pathways in the body. Caution should be taken when using supplements for the methylation cycle because they may cause detox (e.g. die-off, herxheimer) reactions in some people - especially those who have been ill for a long time and have a large amount of toxins and pathogens in the body.

The detox reactions can be unpleasant and potentially serious if you are already significantly affected by ME/CFS. It is recommended by RVK (rich van konyenburg) to start very slowly on the supplements. It is also worth noting that Dr. Myhill's supplement package differs significantly from RVK's in that it uses more nutrients and in larger amounts. As such, Dr. Myhill's treatment may be too much for some people to cope with. If you are sensitive to supplements/food then start with lower doses and increase them to the recommended doses slowly over time.

RVK's clinical trial in ME/CFS showed that most people can fix methylation parameters over a few months with just 1mg hydroxy-b12, 400ug of active folate (methyl or formyl-THF) and a low potency multi-vitamin. Everyone is a bit different though and some people may need more of some nutrients than others.

B12 and folate are by far the most important nutrients for the methylation cycle but they may also provoke the most detox, and associated reactions, in sensitive people.

For a good methylation function it is particularly important to have good amino acid levels. As such, it is important to be able to digest protein well. Unfortunately, it is common for ME/CFS people to have low stomach acid levels which hampers digestion. It is therefore important to check/correct stomach acid levels as part of a methylation cycle treatment.

It is always preferable to do a methylation cycle treatment with a qualified practitioner and to follow your progress with lab tests such as those mentioned on page 12. If you need a practitioner to help you with methylation or other 'biochemical testing and supplementing' then two good UK clinics are: the Breakspear Clinic; and the Optimum Health Clinic.

The Breakspear Clinic

Website: www.breakspearmedical.com

Email: info@breakspearmedical.com

Telephone: 01442 261 333

Address:

Hertfordshire House
Wood Lane
Hemel Hempstead
Hertfordshire HP2 4FD
United Kingdom

The Optimum Health Clinic

Website: www.theoptimumhealthclinic.com/clinic/index.html

E-mail: caroline@TheOptimumHealthClinic.com

Telephone: 0845 226 1762 (local rate number)

Address:

The Optimum Health Clinic
1-7 Harley Street
London
W1G 9QD

The methylation cycle - tests

The following information was provided by a new group member, Will Marsden.

Here are some tests that can be run or may have already been run that can be used to determine methylation problems:

1. The 'Methylation panel' available from vitamin diagnostics in the US or netherlands. This is the current 'gold standard' test for assessing methylation issues and measures many methylation related markers in serum like; active folates, b12, reduced/oxidised glutathione, SAME, etc.
2. The MAP (metabolic analysis profile) available from genova diagnostics in the US or europe. This is a urine test and very easy to do at home. The important methylation markers measured are MMA (measure of adenosylcobalamin) and FIGLU (measure of THF). Also the UAA (urine amino acid profile) is useful to access methionine and other amino acid levels. Some people with CFS have poor protein digestion and are low on amino acids, this will also hamper methylation which relies upon good methionine levels amongst others.
3. If you cant afford the above tests, then any form of glutathione (GSH) measurement such as the 'Full GST' profile offered by acumen lab in the uk is also useful. If glutathione is low then you are likely to have methylation problems. Although it should be noted that a rbc GSH measurement is not always conclusive, since it dosent always reflect overall glutathione status. Serum GSH/GSSG measurement, such as that offered by vitamin diagnostics, is thought to be superior.
4. If you have had full blood counts run and you have raised or even slightly raised MCV or RDW then this can imply B12/Folate deficiency and thus methylation problems. Also a low WBC (white blood cell count) could possibly be due to folate deficiency and so could imply methylation problems too. For detailed information about the hematological effects of B12/Folate deficiency go here: <http://www.me-cfsmethylation.com/viewtopic.php?f=3&t=134>

If you have any questions or need help interpreting tests, please visit this forum:
www.me-cfsmethylation.com.

Vitamin Diagnostics in the Netherlands:

European Laboratory of Nutrients
Reguliererenring 9
3981 LA Bunnik
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Phone: +31 30 2871492
Fax: +31 30 2802688
eln@healthdiagnostics.nl

Vitamin Diagnostics in the US:

Vitamin Diagnostics
Industrial Drive & Route 35
Cliffwood Beach, N.J. 07735 USA
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Email: vitamindia@aol.com
Phone: 1 (732) 583-7773
Fax: 1 (732) 583-7774

Genova Diagnostics Europe (kit order dept.)

Parkgate House
356 West Barnes Lane
New Malden
Surrey KT3 6NB

Mon to Fri 9am til 5.30pm except for bank holidays
24hr Automated Kit Order Line: +44 (0) 208 336 7754
Kit Dispatch Department: +44 (0) 208 336 7763

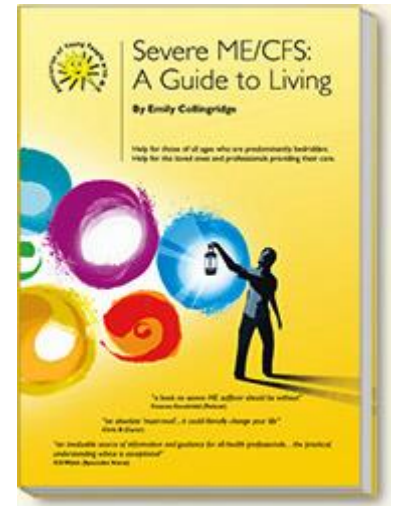
Website: www.gdx.uk.net

Acumen Lab in UK (contact via Biolab UK)

BioLab UK Ltd
Andoversford Industrial Estate
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“Severe ME/CFS: A Guide to Living”

is a comprehensive reference book written by Emily Collingridge, a patient with over twelve years experience of severe ME, in consultation with over thirty patients, carers, friends, relatives and health professionals. Although published by the Association of Young People with ME (known as AYME) as well as containing advice for children and young people, the entire book is suitable for adults of all ages. A4 in size, there are over 130 jam packed pages with guidance on every conceivable area of life with severe ME as well as specific help for carers, partners, siblings, parents, grandparents, friends, doctors, nurses, occupational therapists, physiotherapists, dietitians, speech language therapists, psychologists, social workers and home tutors.



About Emily

Emily Rose Collingridge was born in London in 1981. A passionate and feisty child, she was eager and determined to enjoy everything in life. When she contracted mumps in 1987 she and her family had no idea just how much the future was going to test her strength of character.

For nine years she suffered a huge array of bewildering and worrying symptoms for which doctors could find no cause. Ignorance about ME and poor advice meant that she spent many years struggling to attend school and trying to keep up with her peers when it was far beyond her capabilities. In 1996 she finally received a diagnosis, but by this time was completely dependent on a wheelchair. Thankfully she discovered the Association of Young People with ME (known as AYME), a charity then in its infancy. Despite now being severely affected and almost entirely housebound, she threw herself into work as the organisation’s PR and Fundraising Manager. During this time she spoke to many families who were affected by ME and learnt a great deal about the condition. Her work was recognised nationally by the Whitbread Volunteer Action Awards.

At the age of 21 Emily left AYME to become a project adviser for several other charities, including Home-Start, a leading family support organisation. In 2005 she was forced to stop working due to an extreme deterioration in her health. She continued to decline for nearly two years and went through some extremely traumatic experiences before turning the corner in the Autumn of 2007. Emily remains severely affected and is almost completely bedridden.

Emily writes ...

It is hard to put into words what it felt like to be plunged into the world of very severe ME. The shock, the fear, the pain – physical and emotional – it was totally overwhelming. The endless extreme symptoms and countless practical problems I faced all seemed insurmountable. How could I possibly get through this? How could I possibly cope with this suffering day after day? I could sense that my family and doctors felt the same. We were helpless in the face of a poorly understood and devastating illness. Nobody could give us any answers. Then rare complications meant that I came close to losing my life. If I was to survive we were going to have to come up with our own answers. And with the support of friends who had been there and charities such as AYME as well as a lot of trial and error that is exactly what we did. Somehow life seemed to get a little better and then a little more and then a little more. Eventually people were asking me how I had coped with this, that or the other. They were asking for the answers that we had been forced to learn the hard way. I soon realised that I had something valuable to offer those struggling to live with severe ME. Whilst it seemed rather crazy to write a book when still so ill myself, I knew deep down that it was what I wanted to do. It is a cliché, but, if something positive could come from my traumatic experiences, it would all be easier bear.



An order form for Emily’s book is overlaid and more details can be found at www.severeme.info

Order Form

To order copies of **Severe ME/CFS:A Guide to Living** either go online at www.ayme.org.uk to purchase through Paypal or complete the order form below and send it with a cheque made payable to **AYME Ltd.** to **Severe ME/CFS:A Guide to Living, Association of Young People with ME, 10 Vermont Place, Tongwell, Milton Keynes, MK15 8JA**

I would like copies at £5.99 a copy including p&p

I would like to make a donation to Ayme of £

I enclose a cheque for £

Please send my copies to

Post code:

If you have any questions please just telephone the Association of Young People with ME (AYME) on **08451 23 23 89**.

XMRV research statement by Dr. Derek Enlander on behalf of European Society for ME*

March 11, 2010

Source: <http://www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15213>

ESME, Mar 11: In October the Whittemore Peterson Institute in Nevada published a report on the presence of XMRV virus in ME/CFS patients. This report, published in *Science*, created much excitement in the medical world and in the media.

The report suggested the etiology of ME/CFS was indeed a physical disease, tending to change public opinion.

However, we must temper this excitement with careful research that replicates or denies the thesis. This new research must be careful to replicate or deny the original research with a large cohort of patients and controls.

There are numerous groups with their own agenda who wish to confirm or deny the original research. Large government grants and insurance disability interests are at stake. These groups have rushed to publish unsatisfactory comparative research with anecdotal results, based on a small number of ill-defined patients, stale specimens and differing research methods.

It would be helpful if there was a collaborative effort to test a significant number of the same specimens in different research centers. Perhaps 200 Fukuda criteria and Canadian criteria patients and controls could be divided and tested in multiple centers in a double-blind trial to replicate or deny the original research.

It is time for the psychological and physical researchers to collaborate rather than cast aspersions on each other's work. ESME would support such collaboration.

* ME/CFS/FM specialist Dr. Derek Enlander, MD, is an attending physician at Mt. Sinai Medical Center in New York who also sees patients in the UK.

Dr. Enlander is a Scientific Panel member of the European Society for ME (ESME) - a non-profit Think Tank operated entirely by volunteers and dedicated to discussing the most crucial research and incorporating the best cutting edge information into the education of medical professionals.

‘Scandal in BMJ’s XMRV/CFS research’ by Phoenix Rising Forum member could open can of worms

March 26, 2010

Source: <http://www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15248>

“Parvofighter,” a member of the Phoenix Rising Forum, posted an article on the Forum March 22 titled “Scandal in BMJ’s XMRV/CFS Research.”

The article/expose details Parvofighter’s findings regarding the sources of patient blood samples for the Feb 25 *British Medical Journal* article by van Kuppeveld, et al. which reported failure to find any evidence of XMRV in the blood of CFS patients in the Netherlands.

The Dutch press soon picked up on Parvofighter’s findings and, according to an English translation by Carla from the Diagnose Support site (<http://www.diagnosesupport.com/health>), provides this observation:

“An American patient opens a Can of Worms from Nijmegen”

”The Nijmegen Research of Van Kuppenveld et al. on XMRV and CFS excluded, beforehand, patients infected with XMRV. This is based on the selection of the population which was, amongst other things, based on self reported psychological symptoms. An American patient opens the ‘Can of Worms of Nijmegen’ in a critical and well documented report in spite of all the laudatory discussions in the *British Medical Journal* and elsewhere.”