Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Winter 2011

Future dates

The following ME meetings are open to all members and carers.

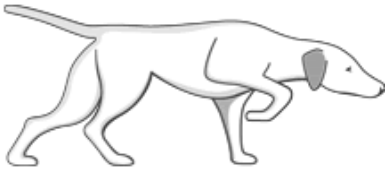
23rd March (Friday) 11am Guildford Holiday Inn
Egerton Road Guildford, GU2 7XZ

23rd April (Monday) 7.30pm The Albany
80 Sydenham Road Guildford, GU1 3SA
There are 2 car parks on Sydenham Road 200yds from the Albany and there are parking bays directly opposite. Otherwise it's parking on the road where possible.

17th May (Thursday) 11am The Seahorse
The Street, Shalford, Guildford, GU4 8BU

27th June (Wednesday) 2.30pm The Anchor
Pyrford Lock, Wisley, GU23 6QW

Benefits and work - guides



The Guildford and West Surrey ME/CFS Group is considering purchasing membership of 'Benefits and work' for the group. It will cost almost £100 so we want to make sure our members want it before we spend the money. Once bought the guides will be emailed for free to members or for a minimal cost can be printed and posted. If you think we should buy the guides please let us know, before 1st April, by emailing Neil at: moonmnky@gmail.co.uk or ring 01276 474263
If ten or more members show interest we will buy the membership for the group.

Are you making a Disability Living Allowance (DLA) or Employment and Support Allowance (ESA) claim or appeal? Or being transferred from Incapacity Benefit to ESA?

Are you worried that the forms are complex and unclear, the medicals may be rushed and inaccurate and the decisions unfair? If so, use our expert, step-by-step guides and give yourself the best possible chance of getting your legal entitlement.

We'll warn you of pitfalls, offer you specialist tips and tactics and guide you through every part of this bewildering process.

www.benefitsandwork.co.uk

UK Government turns new leaf

Source: http://phoenixrising.me/archives/6834
by CORT on January 6th, 2012

The Medical Research Council (MRC) is a government agency responsible for coordinating and funding medical research in the UK. No slouch in the medical world, MRC funded research has led to numerous breakthroughs including, way back in 1918, the discovery that influenza is caused by a virus, the discovery of the structure of DNA in the 1953 and most recently the 2009 Nobel prize for work on ribosomes.

The MRC's record on innovative research pretty much stopped at CFS, however. Bogged down in a purely behaviourist stance towards the disorder, recent MRC funded studies have focused almost entirely on CBT with precious few funds devoted to pathophysiology. Check out the recent MRC studies below.

- Randomised controlled trial of nurse led self-help treatment for primary care patients with chronic fatigue syndrome (1,340,000 US Dollars)
- The PACE Trial – The PACE trial; A RCT of CBT, graded exercise, adaptive pacing and usual medical care for the chronic fatigue syndrome ($4,336,000 US Dollars)
- Chronic Fatigue & Ethnicity ($253,000 US Dollars)
- Training speech therapists in Cognitive Behavioural Therapy to treat Medically Unexplained Dysphonia: A Trial Platform ($404,000 US Dollars)
- United Kingdom Primary Sjogren's Syndrome Registry (UKPSSR) ($ 864,000 US Dollars)

Post Traumatic PACE Syndrome? Something has changed, however. Whether it's due to the poor PACE results, the Rituximab finding or interest stirred up by XMRV the MHC is brewing a different cup of tea this time around.

Topping in at $4,336,000 Dr. White's PACE trials ended up being easily the most expensive study ever done anywhere on ME/CFS and their tepid results must have left a bitter taste in the mouths of MRC group. The PACE trials were the second large and expensive government financed study (Belgium was first) that failed to show that CBT/GET was a cost-effective way (or effective) way of treating CFS.

Note that the list of current projects does not contain follow up funding for Dr. White's PACE trials. Has the MRC soured on CBT? Time will tell but at least this round suggests that it may have.

Instead of a behavioural focus the latest round of MRC studies on CFS are focused ENTIRELY on pathophysiology. The studies may not be ground-breaking and two are peripheral to ME/CFS this slate of studies is a distinct change of 'pace' for the MRC.

Signs of Change at the MRC have been in the air. In 2009 the MRC convened a CFS/ME working group composed of researchers from across the spectrum. In 2010 the MRC's priority list for CFS/ME research included examining the mitochondria, using antiviral agents or immune modulators to reduce symptoms, examining genetics more closely and looking for 'neuro-biological' changes. This is a decidedly different group than the one which funded behavioural or epidemiological studies year after year.

The studies
The MRC is funding both CFS specific and non-CFS specific disorders

CFS specific studies

- Understanding the pathogenesis of autonomic dysfunction in chronic fatigue syndrome and its relationship with cognitive impairment. Principal investigator: Professor Julia Newton
- Modulation of aberrant mitochondrial function and cytokine production in skeletal muscle of patients with CFS by supplementary polyphenols. Principal investigator: Professor Anne McArdle
- Can enhancing slow wave sleep SWS improve daytime function in patients with CFS? Principal investigator: Professor David Nutt Institution: Imperial College London

Newton, the Brain and the ANS - With four ME/CFS studies published in 2011, Dr. Newton's Newcastle group is one of the most productive anywhere. Heavily focused on the autonomic nervous (ANS) system functioning, the Newton study will examine both blood flows to the brain and ANS functioning to see if they can determine where the dizziness and difficulty standing in ME/CFS comes from.

McArdle on the Mitochondria - The McArdle study will use new and improved technology to examine mitochondrial functioning in the muscles. It follows on a series of studies that have suggested problems with muscle functioning including a Newton study last year which demonstrated low muscle pH during exercise and five studies by Fulle in Italy over the past 11 years finding altered mitochondrial gene expression, increased oxidative stress, altered calcium transport and more in muscles of people with CFS.

Nutt's to No Sleep – A Sleep Drug for ME/CFS – The Nutt study will use 'a drug' (not mentioned) that enhances deep-wave sleep to see if increases in energy level and functionality occur once the sleep problem (hopefully) gets worked out.

CFS related studies

- Identifying the biological fingerprints of fatigue. Principal investigator: Dr Wan Ng
- Persistent fatigue induced by interferon-alpha: a new immunological model for chronic fatigue syndrome. Principal investigator: Dr Carmine Pariante

Ng on Fatigue (and Sjogren's Syndrome) – These two studies are reminiscent of NIH attempts to call studies into other disorders "ME/CFS research". This is not to say they might not be helpful; the study to identify the 'biological fingerprints' of Sjogren's Syndrome is intriguing given the high rates of fatigue in that disorder and the possible autoimmune connection in ME/CFS. The fact that Rituximab appears to be effective in reducing fatigue and other symptoms in both disorders suggests that Sjogren's could be a good indirect model for CFS.

Another possible connection concerns the 40 fold increased risk of getting lymphoma present in Sjogren's Syndrome. An unpublished study presented at the Reno conference two years ago suggested that Incline Village residents with ME/CFS had a very high incidence of lymphoma as well.

Sjogren's Syndrome is another female disorder that receives disproportionately low funding. If these researchers find 'biological fingerprints' unique to Sjogren's it's possible they may show up in ME/CFS as well.

Pariante on Interferon alpha and Fatigue - Likewise the interferon alpha study could provide new information on immune causes of fatigue that could inform future ME/CFS research. Interferon-alpha is an anticancer and antiviral drug that has been shown to cause extreme fatigue and flu-like illness in a subset of patients. A Miller study published just last month provided a possible link between IFN-a induced fatigue and CFS. IFN-a provides another possible model into how ME/CFS occurs.

Why the UK Government loves CFS patients more
This isn't chump change the MRC is throwing at ME/CFS either. It's not clear if the money is being spread across the years or is going in one year but if it's all being spent now, the US has a lot of catching up to do to meet the money commitment the UK government is showing to ME/CFS.

The $2.5 million going to these studies is about 5% of the total budget of the MRC (@ 550 million dollars). If the NIH with its 32 billion dollar budget was funding ME/CFS at the same rate it would be spending a whopping 150 million dollars and the CDC would be spending $30 million for a grand total of 180 million dollars a year. (ME/CFS currently gets around $9 million/year). The UK may have been stuck in the doldrums with their overt focus on behavioural treatments but if you ask who's devoting more of their budget to ME/CFS research it's easily the Brits. It appears that for all their wrong-headed research the UK at least considers CFS a serious condition while the US federal establishment continues not to.

Energy expenditure in ME/CFS: immune wastage of energy and Rituximab

by Dr. Sarah Myhill, MD* February 17, 2012
Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=16825

We all have a pot of energy which is available to us to spend over the day. What prevents us spending too much is the symptom of fatigue.

We have to spend that pot of energy just to stay alive in "house-keeping" duties - but in addition mentally, physically, emotionally or immunologically.

In ME/CFS either that pot of energy can be small (because of poor mitochondrial function, poor fuel supply, poor adrenal function, poor thyroid function and so on), or we can be spending energy wastefully.

Of course, the business of pacing is all about spending mental and physical energy judiciously. Many have experienced how energy sapping it is to expend emotional energy.

However, I suspect a greatly overlooked cause of wasting of energy is immunological.

Energy must be expended on daily "house-keeping" duties. I was intrigued to see the following energy expenditure breakdown in Wikipedia:
- Liver 27%,
- Brain 19%,
- Heart 7%,
- Kidneys 10%,
- Skeletal muscle 18%,
- Other organs 19%.

It astonished me that the liver consumes more energy than the heart and brain combined! Much of this has to do with assimilating and detoxing food from the gut!

Immunological energy
I see the immune system to be like the brain, i.e. it is enormously demanding of energy. We all know this - if a healthy person develops influenza, then he becomes bed-bound for two weeks (she becomes bed-bound for a week….!).

Work done by Caroline Pond has demonstrated that when wild animals put on weight, the first place they dump their fat resources is around lymph nodes; i.e., the immune system.

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Bone marrow, of course, is very fatty, so this suggests the immune system is not just demanding of energy, but energy in an intensive form; i.e., fats and oils.

The immune system spends energy fighting infection, which is, of course, highly desirable. However, if it gets its wires crossed, it may end up fighting the body itself (autoimmunity), or fighting substances which do not cause harm, and this is allergy.

However, in ME I suspect there is another immunological waste of energy which has to do with microbes, possibly “allergy” to microbes.

Post-Infectious ME
A great many cases of ME follow viral infection and/or vaccination. In these conditions the immune system is switched on to fight the offending microbe.

In the short term this is highly desirable. To be effective, all vaccinations contain immune adjuvants which are there specifically to fire up the immune system. When this works in our favor, we call it immunity.

However, when it works against us, we call it allergy. Clinically, we know that vaccinations can trigger allergies.

There is no doubt that there are some ME patients who do not recover until they start taking antivirals (see work by Dr. Martin Lerner in my page "Valacyclovir in the treatment of post viral fatigue syndrome,” Sep 2010), antibiotics or antifungals.

In these cases, there is often no overt evidence of infection.

I suspect what is going on here is that these microbes are present in low levels which would not normally cause harm to the body, but the immune system continues to fight.

It is a sort of inappropriate immune activation against microbes or “allergy” to microbes. This is hugely wasteful of energy. Such patients will have a large immunological hole draining their daily energy bucket.

Immune mapping
What we perceive going on in the body is not what is really going on in the body, but it iswhat the brain tells us is going on in the body!

The brain has a complete map of the body, which includes sensory and motor functions. Ref“Phantom Limb Syndrome” by Dr. VS Ramachandran (University of California, San Diego).

It is possible that this could explain the mechanism by which healing and touch therapies such as Bowen therapy, Reiki, Kinesiology, etc. work. These techniques are literally re-mapping the brain to perceive things quickly, or direct motor actions correctly.

It is possible that the immune system has a similar mapping process.

I think of the immune system as having a “map” of what should and should not be present in the body. I imagine it “sniffing” about the place looking for foreigners.

There are many good doctors who have experimented with many different types of immunotherapy, such as neutralization, enzyme potentiated desensitization (EPD) and, of course, homeopathy; and it may well be that they are having their beneficial effects because of this re-mapping of the immune system.

All these mechanisms are characterized by extremely low levels of molecules or antigens being applied with profound effects that cannot be explained by conventional pharmacology.

Treatment of badly educated B lymphocytes
Immune mapping probably takes place in B lymphocytes. They start life in the bone marrow, move into the blood stream, and are educated by the thymus gland and lymph nodes. This takes a few months. The mature B lymphocytes become the decision makers for immune attack or immune tolerance (war or peace!).

Post infectious ME patients may have B lymphocytes constantly at war. These white cells have been badly educated, their wires are crossed.

This therefore gives us a model for treatment.

Either we can re-educate these B lymphocytes or we can kill them, or we can try to reduce the things they are inappropriately reacting against, which may be foods (diet) or microbes (with antimicrobials which could be drug or herbal, change the gut flora with probiotics).

Re-educate B lymphocytes with immunotherapy
Perhaps desensitization with neutralization, EPD or homeopathy are techniques directed at re-educating these B lymphocytes to respond appropriately by remapping the immune system?

In the case of neutralization the result may be immediate. With EPD (and I know much more about this because I have been using EPD for 25 years!) the result is often delayed by a few months, it lasts weeks to months, and then patients may need a top up of the treatment.

Although these desensitisations are largely directed at foods, inhalants and chemicals, some microbial antigens are also included. See “Enzyme Potentiated Desensitisation (EPD) - how it works".

Kill B lymphocytes with Rituximab
This drug is a monoclonal antibody specifically effective against the CD20 receptor on B lymphocytes. It specifically depletes B lymphocytes; i.e., it kills off the standing army – if this army is involved in civil war, then its depletion is a very desirable action!

Rituximab is primarily used in cancer chemotherapy. By pure chance a patient who had severe ME received this drug as part of a treatment for her lymphoma and her ME symptoms disappeared. She was delighted! Her daily energy bucket was no longer being immunologically drained!

This prompted a study by her Norwegian oncologists, Prof Olag Mella and Dr. Oystein Fluge at Haukeland University Hospital, Bergen, to conduct a placebo controlled double blind trial into the effectiveness of Rituximab in ME.

This was done with 15 patients receiving the active preparation and 15 the placebo…
[See “Benefit from B-Lymphocyte Depletion Using the Anti-CD20 Antibody Rituximab in Chronic Fatigue Syndrome: A Double-Blind and Placebo-Controlled Study.”] Rituximab had a highly significant beneficial effect.

What was so interesting about this effect is that it took 2 to 4 months to start, it lasted for 2 to 6 months, then some patients relapsed but some were cured!

This fits very nicely with the time scales I see in my EPD patients – again there is a delayed start, improvement, then top ups required according to the clinical response.

Another way to tackle this problem of inappropriate activation against microbes would be to use therapeutic agents which may be herbal, or prescription medication, to try to reduce the level of microbes so much that the immune system stops reacting.

It may be that this approach explains the success of Dr. Martin Lerner’s work with antivirals, treatments with antibiotics for Lyme disease, and with antifungals for chronic yeast problems.

It is the old story - we have a lot more good questions than good answers, but at least we are asking the right questions!

Glutathione and ME/CFS

Partial source: www.chronicfatiguetreatments.com/wordpress/treatments/glutathione-and-chronic-fatigue-syndrome

An overview of glutathione and ME/CFS is included below. Further information is on page 13.

> Any organism that breathes in oxygen to use (with food) to make energy for living, causes a harmful by-product called free radicals (think radiation) which bombard our cells and can damage or kill them. Our bodies use a range of anti-oxidants (e.g. Vitamins A, C & E, Glutathione) that work together to neutralise the free radicals making them harmless. However, if the balance of free radicals to anti-oxidants favours the free radicals then 'oxidative stress' occurs, which is the term used to refer to the stress/damage that cells experience . Oxidative stress is associated with over 70 illnesses can cause: heart disease, cancer, arthritis, lung disease, fibromyalgia, diabetes, parkinson's, alzheimer's, autoimmune diseases and macular degeneration.
>
> various sources: Wikipedia, www.preventive-health-guide.com/oxidative-stress.html

Glutathione is a very important anti-oxidant in the body and its depletion is often associated with ME/CFS. Glutathione scavenges free-radicals and detoxifies the body of substances like heavy metals and pesticides. It helps maintain the body's energy producing mitochondria and improves immune system function. Studies[1] have found that ME/CFS patients are generally depleted in glutathione and supplementation may help to improve their symptoms.

> Each and every cell in the body is responsible for its own supply of glutathione and must have the necessary raw materials in order to produce it.
>
> Glutathione is always in great demand and is rapidly consumed when we experience any sort of emotional or physical stress, fatigue and even moderate exercise.
>
> Source: http://themaxsite.com/glutathione.html

Dr Paul Cheney (CFS Researcher) believes that glutathione depletion is one of the first issues in CFS patients that should be addressed. Glutathione is important for detox as well as keeping our immune systems from being overrun by viral and mycoplasma infections. Many CFS patients have co-existing Epsten-Barr, HHV6, Mycoplasma infections. Cheney believes that Glutathione supplementation can help stop the replication of these infections.

Glutathione depletion is also found in HIV patients. Glutathione has been show to help stop the replication of the virus in HIV patients.

An overview of supplements that can be taken to increase Glutathione is included later in this article. However, it is important to first note that an important way to increase levels of Glutathione in the body is to make sure that the body is methylating properly.

Methylation

Methylation is a process in the body that is required to sustain important elements of the body such as protein, DNA and neurotransmitters. Without Methylation such elements would degrade and malfunction and we would die in a few days. In Methylation, certain 'Methyl group' chemicals are added to proteins, DNA and other molecules to keep them in good working order.

One of the outputs of methylation is cysteine, which is one of three main components of glutathione. It is cysteine that gives glutathione it's biological activity and it can't be absorbed by the digestive system, so it's not useful as a supplement. The other two components of glutathione, namely glutamic acid and glycine can be digested and are readily available in a western diet. It is the cysteine from methylation, therefore, that is the rate-limiting factor in the creation of glutathione. If the methylation process is not working properly then we are likely to suffer from a lack of glutathione.

[1] http://phoenixrising.me/treatments-2/treatment-protocols/rich-van-konynenburg-ph-d

> Van Konynenburg believes that the fundamental biochemical issue in a large subset of the CFS patients is that the methylation cycle is blocked. The main goal of this treatment approach is to remove this block and restore the methylation cycle. He also believes that glutathione depletion is directly responsible for many of the features of CFS, but that it is usually not possible to normalize the glutathione levels on a permanent basis by direct approaches of glutathione supplementation. Rather, the methylation cycle block must be corrected first, to break the vicious circle that is holding down the glutathione levels.
>
> Source: www.health-choices-for-life.com/glutathione.html

Aside from the creation of cysteine for glutathione, methylation is vital for managing levels of homocysteine. Homocysteine is what is left-over when an important amino acid called methionine is used to methylate protein and DNA. Before it reaches harmful levels the homocysteine must be methylated back into the useful methionine.

Homocysteine is implicated in:

- heart disease and stroke by encouraging the clumping together of platelets;
- higher levels of oxidized LDL cholesterol from reacting with iron and copper ions to produce free radicals;
- dementia and alzheimer's;
- liver disease;
- depression; and
- aging in general.

An article discussing methylation and the supplements to take to ensure that your body is methylating properly was included in the Spring 2010 newsletter that is available in the members area of our group website: www.rescue.myzen.co.uk

However, as a basic guide the relevant supplements are:

- B6
- B12
- B9 (folic acid)
- Tri-Methyl-Glycine TMG
- SAMe.

It is important to note that to ensure that you are able to use the B vitamins successfully you should buy the active versions which are ready for the body to use. The cheaper typical versions, non-active ones, require a healthy body to convert them into their active form.

The active versions are called:

- pyridoxyl-5-phosphate (B6)
- Methylcobalamin (B12)
- folinic acid (B9)

Specific buying examples are included on page 11. Please note that both methylation and glutathione are powerful processes in the body and taking associated supplements should be done after discussing them with your GP/doctor.

Supplements for increasing glutathione
Many supplements containing glutathione or cysteine aren't absorbed well by the body and are therefore not useful ways of significantly raising glutathione. There are, however, different ways to increase the amount of intracellular glutathione in your body.

N-acetyl–cysteine (NAC)
NAC is a dietary supplement that has been proven to boost glutathione levels in the body. NAC has to be taken several times a day to be effective. Side-effects that have reported, including rash, wheezing, nausea, vomiting, cramps and diarrhoea. More research needs to be done on the effects of long term usage of N-acetyl-cysteine before we can evaluate its safety over the long term.

A recently published study from the University of Virginia School of Medicine found that NAC can lead to pulmonary arterial hypertension (PAH), a serious condition characterized by high blood pressure in the arteries that carry blood to the lungs.

Melatonin
Melatonin is a hormone that naturally occurs in the brain. As a supplement Melatonin is typically used as a sleep aid and for resetting the body clock during jet lag. However, Melatonin is a powerful anti-oxidant and effectively raises glutathione levels. Although Melatonin is freely available and in wide use the long term safety of melatonin has not been well established.

Glutamine
Glutamine is the most abundant free amino acids found in the body. It is useful in raising glutathione. One of the few amino acids that crosses the blood-brain barrier, it is normally plentiful in the diet today.

There are many functions of glutamine, including its role in metabolising and maintaining lean muscle. It can also build up your immune system, play a role in anti-cancer therapy, boost brain function, and detoxify the body.

Glutamine supplies the body with glutamate, one of the three amino acids that raise glutathione, and it is the second most important component after cysteine. Glutamate is found in many plant and animal sources, but is easily destroyed by cooking.
It is also found in raw spinach, parsley, and raw meat, but with the health risks associated with the latter, is not recommended. Completely healthy individuals don't need supplemental glutamine. Any serious use of this supplement for help in how to raise glutathione should be monitored by a health care professional.

Lipoic Acid
This is also commonly referred to as Alpha-Lipoic Acid. The roles of this substance are as an antioxidant, neutralizer of toxins and heavy metals, and recycler of other antioxidants like Vitamin C and Vitamin E. It occurs naturally in the body, and is also available on the shelves of health food stores. it can also be found in small amounts in foods like spinach and broccoli.

Lipoic Acid works by keeping glutathione in its reduced state. This is good, because in its reduced stated, glutathione can do its job as an antioxidant. So they have a partnership of sorts. One reason glutathione is called the Master Antioxidant is because it also helps to keep lipoic acid in it's reduced state as well.

There is some research demonstrating that a lipoic acid supplement is best taken along with L-Carnitine for the best results in raising glutathione.

There are promising results with lipoic acid being demonstrated with medical studies. For some, there are short term side effects, and so more research is being done on this substance to see what other benefits it may have in addition to raising glutathione.

Supplements for increasing glutathione continued…

Silymarin

Silymarin is the substance extracted from the milk thistle plant. As such, at times, these terms are used interchangeably.

Silymarin has been used by herbalists for centuries to treat a variety of liver disorders, like cirrhosis or hepatitis. It seems to stimulate the growth and regeneration of injured liver cells. It can also act as a free radical scavenger, enhancing detoxification in the liver. There are ongoing studies demonstrating silymarin's effectiveness in raising glutathione levels. Recommended doses vary greatly, from 50- 500 mg a day. Toxic reactions can include gas, cramps, and diarrhea.

Since it may lower blood sugar, it should be used with caution by diabetics. Liver diseases, including auto immune liver disease, should always be treated with the assistance of a health care professional.

Glutathione injections

Typically administered by injection, or intravenously (IV), this is very effective in how to raise glutathione blood plasma concentrations temporarily, but does not raise it in the lymphocytes where you need it to build up your immune system.

A standard dosage may be mixed with saline, and is best administered alone rather than combined with other antioxidants. It can be injected up to three times a week. While somewhat effective short-term, it is expensive, and requires the assistance of a health professional. Since the glutathione molecule is too large to pass into your white blood cells, it does not feed your immune system and help you to ward off illness.

Another drawback to IV glutathione administration is the short half life. Glutathione is raised, but it typically only lasts a few hours in the body and so has to be administered several times. Blood glutathione levels will peak following administration, and then taper off in some cases to even lower levels of glutathione than you had before the glutathione injection. Long term, this would not be helpful to you.

Given these drawbacks, getting glutathione injections is less than desirable. The best way for how to raise glutathione is to manufacture it in the cell, where it lasts longer and also builds up your immune system. As an alternative, injections work very well and have been shown in studies to have a beneficial effect on many disease states including Parkinson's Disease and Autism.

Undenatured Whey Protein

Also called bioactive whey protein. Undenatured whey protein is a globular protein isolated from whey. The most common form of whey available comes from cow's milk. Raw milk contains about 20% whey. Because of pasteurization and the legal requirements regarding this today, all milk being sold commercially now is pasteurized and thus "dead" from a biological standpoint. So, the milk that you buy in the grocery store does not contain undenatured whey protein and will not help you to learn how to raise glutathione.

All whey proteins that you can buy in the store are denatured, which means they are not bioactive. If you can buy it in a tub, and it comes in vanilla, chocolate, and strawberry, it is great as a dietary source of whey, but has been "killed" in this way and will have no effect on how to raise glutathione levels in your cells.

It is not undenatured whey protein, and it is not bioactive, even if the label says it is. It will not help you to know how to raise glutathione. To have a measurable affect on glutathione levels, the protein must be bioactive or undenatured. This will also help to build up your immune system. What this means is the whey must be processed in such a manner that the heat-sensitive proteins and amino acids are preserved. When these amino acids are preserved, you end up with an efficient way to deliver cysteine to the cells. This is an important factor to consider when learning how to raise glutathione in your cells.

An example buying solution for methylation and glutathione support
The following is an example of the supplements and doses for supporting methylation. As already mentioned earlier… please note that both methylation and glutathione are powerful processes in the body and taking associated supplements should be done after discussing them with your GP/doctor.

Methylation support

- AOR advanced B complex (90 vegi caps) – Take 1 a day (not the 3 stated on bottle)
  £35.60 from www.aoreurope.co.uk

  1 tablet contains:
  B1(Benfotiamine) 100mg
  B2 (Riboflavin) 7.5mg
  B3 Niacin (from Inositol Hexanicotinate) 312mg
  B5- Pantothenic Acid (Pantethine) 300mg
  B6 (Pyridoxal-5-phosphate) 100mg
  B12 (Methylcobalamin) 1000mcg
  Folic Acid (5-Methyltetrahydrofolate) 1000mcg
  Biotin 500mcg
  Choline (Bitartrate) 600mg
  Inositol (from Inositol Hexanicotinate) 384mg

- Swanson Ultra Methylcobalamin **B12** (5mg, 60 tablets) – Take 1 a day (under tongue)
  £9 from www.amazon.co.uk

- Doctor's Best, **SAMe** 200, (60 enteric coated tablets) – Take 1 a day
  £26 from www.amazon.co.uk

- Now Foods, TMG (Trimethylglycine), extra strength (1,000mg, 100 tablets)
  Take 1 a day
  £14 from www.amazon.co.uk

Glutathione support

- Enerex N-Acetyl Cysteine (90 x 1000mg tablets) - Take 1 a day
  £23 from www.amazon.co.uk

- Doctors Best Alpha Lipoic Acid (60 X 600mg veggiecaps) – Take 1 a day
  £12 from www.amazon.co.uk

- Milk Thistle 5600mg – delivers 150mg Silymarin (90 tablets) – Take 1 a day

- PINK SUN - Everyday Whey Grass Fed Hormone Free Whey Protein Concentrate Powder 420g Unflavoured

  £16.50 from www.amazon.co.uk

  Premium quality undenatured whey protein concentrate powder

  As a dietary supplement blend 25g with water or milk to desired consistency. To create delicious smoothies add fruit, yoghurt.

New mitochondrial function analysis technique to be used in ME/CFS research at University of Liverpool

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=16723
Original source: based on University of Liverpool news release, Dec 21, 2011

Researchers at the University of Liverpool will be the first to implement a newly developed lab technique that is more sensitive to identifying mitochondrial function within the muscle's fibers - a technique they believe could reveal the causes of Chronic Fatigue Syndrome (ME/CFS).(And one, we would hope, that could be applied in the study of fibromyalgia patients' muscle fibers as well.)

ME/CFS is a severely debilitating illness, characterized by prolonged fatigue that can be triggered by minimal activity. Fatigue is accompanied by symptoms that may include painful muscles and joints, disordered sleep patterns, gastric problems and cognitive impairment.

- The causes of the condition are unknown, but some studies have suggested that a defect in the energy producing components of muscle cells, called mitochondria, could be responsible.
- Other studies, however, have not been able to demonstrate this defect.
- It is thought that limitations in the methods used to determine mitochondrial function in human muscle fibers could be the reason why the causes of ME/CFS have been difficult to explore.

The Liverpool team anticipates that using the new mitochondrial analysis methods will:

- Establish whether skeletal muscle mitochondria in patients with ME/CFS are indeed dysfunctional,
- And if so might explain muscle fatigue and further complications leading to chronic inflammation and pain.

According to team member Professor Anne McArdle, a specialist in the University's Pathophysiology Research Unit:

- "The mechanisms that lead to debilitating muscle fatigue and pain in CFS patients are unknown.
- "The time required for diagnosis further complicates the identification of the factors responsible for triggering the illness.
- "Reversal of the severe fatigue that follows remains the most promising form of treatment."
- "Scientists have hypothesized that the mitochondria malfunction, significantly reducing the energy supply to the muscle cells that allow the body to carry out its daily activities.
- "The pain and inflammation that follows can cause further mitochondrial abnormalities and so the vicious cycle of events continues."

The University of Liverpool is participating with the Universities of Newcastle and Sheffield in development of a UK-based Center for Integrated Research into Musculoskeletal Ageing – CIMA (http://www.cimauk.org).

The glutathione/methylation depletion theory of ME/CFS by Rich Von Konynenburg

1. To get an isolated case of CFS (I'm not talking here about the epidemics or clusters), you have to have inherited some genetic variations from your parents. These are called polymorphisms or single-nucleotide polymorphisms. We know what some of the important ones are, but we don't know all of them yet. This is a topic that needs more research.

2. You also have to have some things happen in your life that place demands on your supply of glutathione. Glutathione is like a very small protein, and there is some in every cell of your body, and in your blood. It protects your body from quite a few things that can cause problems, including chemicals that are toxic, and oxidizing free radicals. It also helps the immune system to fight bugs (bacteria, viruses, fungi) so that you are protected from infections by them.

3. Oxidizing free radicals are molecules that have an odd number of electrons, and are very chemically reactive. They are normally formed as part of the metabolism in the body, but if they rise to high levels and are not eliminated by glutathione and the rest of the antioxidant system, they will react with things they shouldn't, and cause problems. This situation is called oxidative stress, and it is probably the best-proven biochemical aspect of chronic fatigue syndrome.

4. There are a variety of things in your life that can place demands on your glutathione. These include physical injuries or surgery to your body, exposure to toxic chemicals such as pesticides, solvents, or heavy metals like mercury, arsenic or lead, exposure to infectious agents or vaccinations, or emotional stress that causes secretion of a lot of cortisol and adrenaline, especially if it continues over a long time. Just about anything that "stresses" your body or your mind will place a demand on glutathione. All people experience a variety of stressors all the time, and a healthy person's body is able to keep up with the demands for glutathione by recycling used glutathione molecules and by making new ones as needed. However, if a person's body cannot keep up, either because of extra-high demands or inherited genetic polymorphisms that interfere with recycling or making glutathione, or both, the levels of glutathione in the cells can go too low. When glutathione is properly measured in most people with CFS (such as in the Vitamin Diagnostics methylation pathways panel), it is found to be below normal.

5. One of the jobs that glutathione normally does is to protect your supply of vitamin B12 from reacting with toxins. If left unprotected, vitamin B12 is very reactive chemically. If it reacts with toxins, it can't be used for its important jobs in your body. A routine blood test for vitamin B12 will not reveal this problem. In fact, many people with CFS appear to have elevated levels of B12 in their blood, while their bodies are not able to use it properly. The best test to reveal this is a urine organic acids test that includes methylmalonic acid. It will be high if the B12 is being side-tracked, and this is commonly seen in people with CFS.

6. When your glutathione level goes too low, your B12 becomes naked and vulnerable, and is hijacked by toxins. Also, the levels of toxins rise in the body when there isn't enough glutathione to take them out, so there are two unfortunate things that work together to sabotage your B12 when glutathione goes too low.

7. The most important job that B12 has in the body is to form methylcobalamin, which is one of the two active forms of B12. This form is needed by the enzyme methionine synthase, to do its job. An enzyme is a substance that catalyses, or encourages, a certain biochemical reaction.

8. When there isn't enough methylcobalamin, methionine synthase has to slow down its reaction. Its reaction lies at the junction of the methylation cycle and the folate cycle, so when this reaction slows down, it affects both these cycles.

9. The methylation cycle is found in all the cells of the body (not counting the red blood cells, which are unusual in a lot of ways). The methylation cycle has some important jobs to do. First, it acts as a little factory to supply methyl (CH3) groups to a large number of reactions in the body.

Some of these reactions make things like creatine, carnitine, coenzyme Q10, phosphatidylcholine, melatonin, and lots of other important substances for the body. It is not a coincidence that these substances are found to be low in CFS, so that people try taking them as supplements. Not enough of them is being made because of the partial block in the methylation cycle. The methylation cycle also supplies methyl groups to be attached to DNA molecules, and this helps to determine whether the blueprints in the DNA will be used to make certain proteins according to their patterns. The "reading" of DNA is referred to as "gene expression." Methyl groups prevent or "silence" gene expression. Overexpression of genes has been observed in CFS patients, and I suspect this is at least partly due to lack of sufficient methylation to silence gene expression.

10. Another thing that the methylation cycle does is to regulate the overall use of sulfur in the body. Sulphur comes in from the diet in the form of amino acids in protein (methionine and cysteine) and as taurine and some as sulphate. The methylation cycle regulates the production of the various substances that contain sulphur that are needed by the body. The levels of various sulphur metabolites are often found to be abnormal in people with CFS.

11. One of the most important sulphur-containing substances in the body is glutathione, so now you can see how this is starting to look like a dog chasing its tail! The thing that causes chronic fatigue syndrome to be chronic, and keeps people ill for years and years, is this interaction between glutathione, vitamin B12, and the methylation cycle. When glutathione goes too low, the effect on vitamin B12 slows down the methylation cycle too much. The sulphur metabolites are then dumped into the transsulfuration pathway (which is connected to the methylation cycle) too much, are oxidized to form cystine, pass through hydrogen sulphide, and are eventually converted to thiosulfate and sulphate and are excreted in the urine. This lowers the production of glutathione, which requires cysteine rather than cystine, and now there is a vicious circle mechanism that preserves this malfunction and keeps you sick.

12. That's the basic biochemical mechanism of CFS. I believe that everything else flows from this. As you know, there are many symptoms in CFS. I won't discuss all of them in detail here, but here's how I believe the fatigue occurs: The cells have little powerplants in them, called mitochondria. Their job is to use food as fuel to produce ATP (adenosine triphosphate). ATP acts as a source of energy to drive a very large number of reactions in the cells. For examples, it drives the contraction of the muscle fibers, and it provides the energy to send nerve impulses. It also supplies the energy to make stomach acid and digestive enzymes to digest our food, and many, many other things.

When glutathione goes too low in the muscle cells, the levels of oxidizing free radicals rise, and these react with parts of the "machinery" in the little powerplants, lowering their output of ATP. So the muscle cells then experience an energy crisis, and that's what causes the fatigue. Over time, because of the lack of enough glutathione, more problems accumulate in the mitochondria, including toxins, viral DNA, and mineral imbalances. These have been observed in the ATP Profiles and Translocator Protein test panels offered by Acumen Lab in the UK.

13. There are explanations that flow from this basic mechanism for other aspects of CFS. I haven't figured out explanations for all of the aspects of CFS, but I do think I understand a large number of them in some detail, and I've been able to explain enough of them that I believe this mechanism will account for the rest as well, if we can figure out the underlying biochemistry. My 2007 IACFS conference poster paper presented outlines of many of these explanations.

14. The involvement of infections by bacteria, viruses and fungi appears to have two aspects in CFS. First, as mentioned above, infectious agents can act as one of the stressors that initially bring down the level of glutathione and produce the onset of isolated cases of CFS in people who are genetically susceptible. I suspect that the clusters or epidemic occurrences of CFS (such as at Incline Village in the mid-80s) were caused by particularly virulent infectious agents, such as powerful viruses, and the genetic factor is less important in these cases.

15. Second, when a person's glutathione, methylation cycle, and folate cycle are not operating normally because of the vicious circle described above, the immune system does not function properly. In this case, viruses and bacteria that reside inside our cells and that are always in the body in their dormant, resting states are able to reactivate and produce infections, which the immune system is not able to totally put down. This accounts for the observation that most of the viral and intracellular bacterial infections seen in CFS patients are caused by pathogens that most of the population is carrying around in their dormant states.

16. Third, when the immune system's defences are down, a person can catch new infections from others or from the environment, and the immune system is not able to defeat them, so they accumulate over time. Dr. Garth Nicolson has found that the longer a person has been ill, the more infections they have, on the average.

17. Other things that accumulate over time are various types of toxins, because the detox system depends to a large extent on the sulphur metabolism, and it will not be operating properly as long as the person has CFS. The body stores much of these toxins in fat, but as the levels get higher, they begin cause problems throughout the biochemistry of the cells. Many people with CFS have been tested for toxins (most commonly the heavy metal toxins, which are the most easily tested) and they are commonly found to be elevated.

18. The longer a person is chronically ill with CFS, the more toxins and infections accumulate in their body, and the more symptoms they experience. This explains why the disorder changes over time, and why some people become extremely debilitated after being ill for many years.

19. The main key to turning this process around is to help the methionine synthase enzyme to operate more normally, so that the partial block in the methylation cycle and the folate cycle are lifted, and glutathione is brought back up to normal. That is what the simplified treatment approach is designed to do, and so far, the evidence is that it does do these things in most people who have CFS. I recommend that people with CFS have the Vitamin Diagnostics methylation pathways panel run to find out if they do in fact have a partial methylation cycle block and glutathione depletion before deciding, with their doctors, whether to try this treatment. This also provides a baseline so that progress can be judged later on by repeating it every few months during the treatment. Symptoms may not be a good guide to judge progress during treatment, because detoxing and die-off can make the symptoms worse, while in fact they are exactly what is needed to move the person toward recovery.

20. The main question I'm working on now is what else needs to be done to bring people to recovery? I don't have complete answers to this question yet. Many people may recover from this treatment alone, but it is proving to be a slow process, and we will need more time to see how this will work out. It does appear that people who suffer from illness due to toxic molds do need to remove themselves from environments where these are present. The small amount of evidence I have so far suggests that people who have Lyme disease will need to have that treated in addition. I'm not sure about certain viral infections. They may also need to be treated. We still have a lot to learn, but I'm convinced that the mechanism I have described above is the core of the abnormal biochemistry in CFS, and correcting it needs to be cornerstone of the treatment.

Source: http://aboutmecfs.org.violet.arvixe.com/RsRch/GSHSimpleExplanation.aspx