Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

March 2014

Future dates

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

20th March 2014 (Thursday) 12 noon The White Hart
White Hart Lane, Wood Street Village, Guildford, Surrey, GU3 3DZ

Directions from Guildford - Join A323 towards Aldershot. Turn left at the roundabout just after The Rydes Hill Prep School, onto Broad Street, sign-posted to Wood Street. Drive through Wood Street until you get to the Village Green, then turn left immediately after the green and right onto White Hart Lane. The pub is 50 yards down on the right.

Annual General Meeting (AGM)
8th April 2014 (Tuesday) 7.30pm The Seahorse
The Street, Shalford, Guildford, GU4 8BU

All members and carers are welcome to the AGM. The committee members will provide a brief overview of the group's activity over the last year and discuss the group's future direction with those who attend the AGM.

7th May 2014 (Wednesday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU

5th June 2014 (Thursday) 7.30pm White Lyon & Dragon
Perry Hill, Worplesdon, Guildford, GU3 3RE

Just along from the Worplesdon Place Hotel, The White Lyon and Dragon is a Thai restaurant in Worplesdon that has both a bar/food section and restaurant. Tuesday night is discounted making the quality food very reasonably priced. Of course, you can simply turn up to have a soft-drink or tea.

In brief: Autoimmunity and ME

Source: http://phoenixrising.me/archives/19682
By Andrew Gladman October 8th, 2013

In the last few years it's fairly safe to say that the topic of autoimmunity has moved from a fairly unknown entity in the ME field to perhaps the leading hypothesis in many peoples' eyes. This surge in attention likely comes from the rituximab trials in Norway undertaken by Doctors Fluge and Mella. By chance they discovered that ME patients, who then went on to develop lymphoma, treated with rituximab for their cancer also experienced significant, albeit transient, relief from near all of their ME symptoms. These published and ongoing trials appear to be suggesting that up to 67% of ME patients are responding well to this drug. Given the B-cell destroying mechanism of rituximab this has led the Norwegian doctors to conclude that ME is perhaps best described as an autoimmune condition mediated primarily by autoreactive B-cells.

What is Autoimmunity?
Autoimmunity is generally regarded as the lost ability of the body to differentiate between certain parts of the normal organism's anatomy and pathogenic invaders. All cells and tissues within an organism have molecules known as antigens on their surface that act simply like little flags, allowing the patrolling cells of the immune system to recognise them as a part of the organism ('self'). If for some reason the circulating immune cells lose the ability to recognise these flags, the cells displaying them are then treated as a foreign invader ('non-self') and an immune response is initiated against them. The body now attacks itself. This is often described as a loss of ability to differentiate between self and non-self.

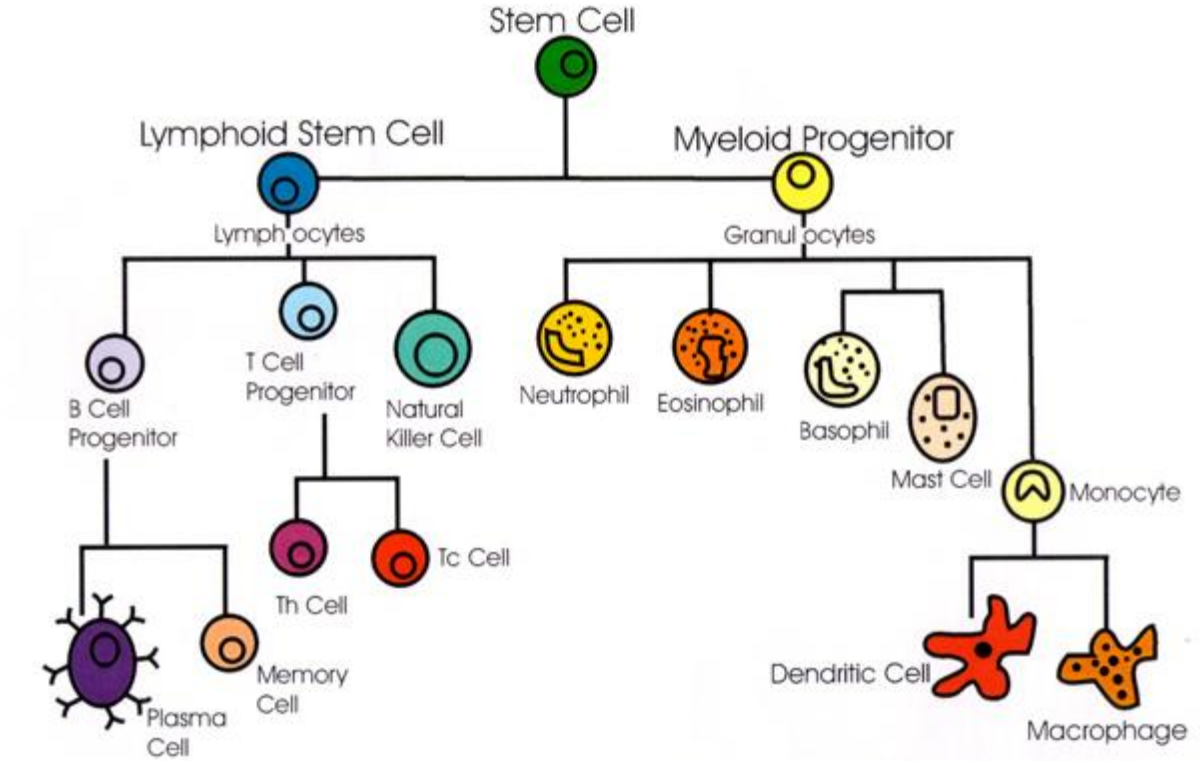
The immune response is generally comprised of an innate component and an adaptive component:

> **Innate component**
> A fast-acting, non-specific innate response, which is the first line of defence (e.g. macrophages and to a degree natural killer cells - however these cells play a role in both the adaptive and innate systems.)
>
> **Adaptive component**
> A slower but specific and targeted adaptive response (e.g. B-cells and T-cells.)

The innate response, as the first line of defence, also helps trigger the adaptive response however the adaptive response is considered the major player in autoimmunity. These responses interact with one another through various immune cells and chemical messages which they secrete such as cytokines. Until quite recently the innate immune system was thought to be of little importance in autoimmune conditions, however it is now clear that the inability of the innate immune system to recognise self often results in the initiation of inflammatory mechanisms in autoimmune diseases.

The adaptive response is comprised of T-cells and B-cells (sometimes referred to as lymphocytes). There are numerous different kinds of T-cells and each has its own job to do. Some send chemical instructions in the form of cytokines to the rest of the immune system, signalling and triggering responses – allowing the body to produce the most effective 'weapons' against the invading pathogens. Other types of T-cells recognise and kill infected cells directly. B-cells produce small proteins known as antibodies which bind to the antigens of invading pathogens sticking them together and alerting the other cell of the immune system to their presence. In a normal immune response the antigen targeted will be on the surface of a virus or bacterial pathogen, however, in autoimmunity the target for the antibody is an antigen on the surface of a human 'self' cell. Antibodies are detected by T-cells as well as cells involved in the innate immune response, which may then in turn attack and the destroy the cell through inflammatory and other mechanisms.

Diagram 1: Cells of the immune system



The left branch represents the cells of the adaptive immune response which involves B and T cells. The right branch are the cells of the innate immune response. There are many interactions between these two arms, with nearly every cell having mechanisms to communicate with all the other immunological cells.

It is important however to realise that the involvement of each system in autoimmune diseases differs greatly. Not all autoimmune diseases involve inflammatory mechanism and not all involve antibody production. It is a topic of great debate in autoimmunity whether the B-cells or T-cells are the initiating factor, however it appears that autoimmunity has a wide spectrum and certain cells and mechanisms are more involved in some diseases than others.

Under the heading of autoimmunity there exist hundreds of different conditions which are fundamentally differentiated by which cells, tissues or organs are targeted by the aberrant immune response. In theory, any cell type could be the target for such an immune response which explains the wide differentiation in symptoms between different autoimmune diseases – through the damage, dysfunction or destruction of many different cells.

Generally autoimmune diseases are grouped into two types: local and systemic. Local autoimmune diseases are autoimmune diseases where the cells being attacked are specific to only one tissue or organ in the body. Local autoimmune conditions include type 1 Diabetes and Coeliac disease. In systemic autoimmune diseases however, the cell being targeted has a broader range or roles in numerous different organs and tissues within the body. As such, in systemic autoimmune diseases the symptoms are often more extensive and damage cause by the immune response is often more widespread: examples being Lupus and rheumatoid arthritis.

The trouble lies however in that many of the symptoms of autoimmune diseases are quite non-specific which makes diagnosis of many autoimmune diseases quite difficult unless there are specific biomarkers known, whether this be autoantibodies or otherwise, or significant changes in the standard laboratory tests.

Why is autoimmunity important to ME?
The idea of an aberrant immune response is nothing new to the field of ME research. Following the Lake Tahoe outbreak, after which ME/CFS came to the forefront of many doctors and researchers minds, it has been well established and accepted that the immune system in ME patients is not working as intended. Symptoms such as swollen lymph nodes and the characteristic sore throat in ME all point towards a dysregulated immune response and the predominance of ME in women ,with estimates that typically the ME/CFS cohort is comprise 75-85% with women. is further compounding evidence that ME could well be an autoimmune condition, given that this is often the case with autoimmune conditions; it is of note that this is also the case in many psychological diseases, however, this sex predominance is much more pronounced in autoimmune diseases and ME.

In recent years, the evidence continues to mount for the possibility of autoimmunity as a central mechanism within ME. There is evidence of dysregulation in cytokines – substances produced by cells of the immune system which have effects upon other cells – as reported very recently by Dr. Lipkin. There is also evidence, although somewhat disparate, of generic autoantibodies being found in ME patient blood samples. In a recent statement, Dr. Charles Shepherd, Honorary Medical Adviser of The ME Association, quite eloquently summed up these findings:

“A wide range of immune system abnormalities have been reported in ME/CFS. These include the presence of low levels of autoantibodies in some people. Autoantibodies are antibodies that can harm normal body tissues. Among the autoantibodies that have been reported in research studies in ME/CFS are antinuclear antibodies and rheumatoid factor – typically in low concentrations without evidence of lupus or rheumatoid arthritis. Antibody to thyroid gland and other tissues are occasionally reported. There is also an interesting report indicating that antinuclear antibodies, rheumatoid factor and anti-Ro may be present in some people with ME/CFS and a Sjogren’s Syndrome-like presentation.”

Autoimmunity may appear to be something of a revelation, however there have been numerous hypotheses suggested for how different autoimmune mechanisms and loops could explain and be the causative agent for ME. First there is the hypothesis of Dr. Kenny De Meirleir that Plasmacytoid dendritic cells (a sentinel cell and part of the innate immune system that circulates in the blood steam) are autoreactive to Human Endogenous Retrovirus (HERV) proteins – HERVs being viral remnents that remain in the human genome and being passed from parent to child over many generations. Generally they are considered harmless and non-functional, however some may occasionally produce proteins which could act as a target for an autoimmune response. This hypothesis is discussed at much greater length in a recent article by Joel for Phoenix Rising.

Another hypothesis is that autoimmunity may be targeted towards molecules known as vasoactive neuropeptides. These molecules are small peptides comprised usually of around 20-30 amino acids residues. These molecules have numerous functions within the body including acting as neurotransmitters, vasodilators and also play a role in immune regulation. Such an autoimmune response would likely deplete these peptides hence causing the wide array of nondescript and seemingly unrelated symptoms ME patients experience. Interestingly such depletion of these molecules would be virtually undetectable through standard laboratory tests.

Doctors Fluge and Mella are themselves still working on their own hypothesis to explain their positive findings with rituximab which is due for publication, along with results from their latest trial of rituximab, imminently. It is clear that B-cells may be of great importance for the disease pathology of ME. Given that the Invest in ME/UCL rituximab trial is also now well on its way to being funded, the autoimmune hypotheses are now beginning to gain more attention and momentum as time progresses. Hopefully this new ‘hot topic’ in ME research holds more answers in store for us going forwards.

Pulsed Electromagnetic Field Therapy

By Andrew Fulton (Guildford ME Group Treasurer)

Pulsed Electromagnetic Field Therapy (PEMFT or PEMT) uses weak, low-frequency pulsed electromagnetic fields for the benefit of health. It can be applied to a specific area of the body, or the whole body, typically via a mat that you lie down upon.

It is believed that PEMT stimulates cellular energy and repair. Dr Pawlcuk, an expert in the field, explains how the increase in cellular energy affects our overall health:

> "All cells need energy to function. Cellular energy requires ATP (Adenosine Triphosphate) and is fundamental to all cell and body functions and is necessary to sustain life itself. ATP regulates cell metabolism by transporting chemical energy within our cells. Low ATP levels cause our cells to be sick, and decreases their ability to heal, regenerate, or function properly. Through the increased motion of ions and electrolytes, magnetic fields help cells increase their energy (or "charge") by up to 500%...." leading to "increased circulation, enhanced muscle function, decreased inflammation, and blood oxygenation" [1]

The increase in cellular energy may explain why studies have shown that PEMT can be beneficial to a variety of medical conditions including: bone fractures, wound healing, Multiple Sclerosis, Arthritis, and Fibromyalgia [2–7].

NASA have studied PEMT and concluded that it could be used to repair traumatised tissues and moderate some neurodegenerative diseases [8]. More studies can be viewed at the following link: www.wellnessdevices.net/pemf-clinical-studies.html

Although there are no direct studies on ME/CFS, there are studies on Fibromyalgia and many anecdotal reports of patients improving through the use of PEMT.

PEMT is generally considered safe and some devices are approved by the FDA in the USA, however there no studies that demonstrate the long-term effect of PEMT. More conclusive research in some areas is needed, so it's still an experimental treatment to some extent. There are a number of contra-indications which can be viewed at the following link: http://drpawluk.com/education/contraindications

PEMT and me

During my illness I have struggled with food and nutritional supplement sensitivities. One of my doctors told me that she has seen, from her own clinical study, that PEMT reduces food sensitivity.

I decided to trial a PEMT system by BEMER but as it was too strong for me, I switched to using a PEMT system by IMRS; the IMRS system has a setting for sensitive individuals, it uses more effective technology (that is in-line with the recommendations of the NASA trial), and is less expensive than the BEMER system.

By using the IMRS PEMT system regularly over the last year my ME has improved. Although my sensitivities are still a problem, they have improved, and my energy levels have improved significantly.

A Lyme disease and ME/CFS sufferer, who found the IMRS PEMT system fundamental to her recovery, set up a place for people to try, hire and purchase the system. It's called "The Intelligent Wellness Lounge" in is based in St Albans.

Alternatively, you can hire/purchase a system directly from IMRS or an associated therapist. You may be able to have a free trial, as I did, before deciding whether to purchase the unit. The IMRS PEMT system costs about £1300 pounds to own. Hire prices are likely to vary.

Further reading:

IMRS:

www.intelligentwellnesslounge.co.uk/imrs.html
www.imrs.com/en/the-system/imrs-systems.html
www.imrs2000reviews.com/

BEMER:

http://bemerhealth.co.uk/product_detail_3000.html

General PEMT info:

http://drpawluk.com/education/new-to-magnetic-fields/
www.wellnessdevices.net/pemf-clinical-studies.html

References

1. PEMF Facts for Beginners - Dr. Pawluk. at <http://drpawluk.com/education/new-to-magnetic-fields/>

2. Stiller, M. J. *et al.* A portable pulsed electromagnetic field (PEMF) device to enhance healing of recalcitrant venous ulcers: a double-blind, placebo-controlled clinical trial. *Br. J. Dermatol.* **127,** 147–54 (1992).

3. Hug, K. & Röösli, M. Therapeutic effects of whole-body devices applying pulsed electromagnetic fields (PEMF): A systematic literature review. *Bioelectromagnetics* (2011). doi:10.1002/bem.20703

4. Shupak, N. M. *et al.* Exposure to a specific pulsed low-frequency magnetic field: a double-blind placebo-controlled study of effects on pain ratings in rheumatoid arthritis and fibromyalgia patients. *Pain Res. Manag.* **11,** 85–90 (2006).

5. Smith, T. L., Wong-Gibbons, D. & Maultsby, J. Microcirculatory effects of pulsed electromagnetic fields. *J. Orthop. Res.* **22,** 80–4 (2004).

6. Sutbeyaz, S. T., Sezer, N., Koseoglu, F. & Kibar, S. Low-frequency pulsed electromagnetic field therapy in fibromyalgia: a randomized, double-blind, sham-controlled clinical study. *Clin. J. Pain* **25,** 722–8 (2009).

7. Haase, R., Piatkowski, J. & Ziemssen, T. Long-term effects of Bio-Electromagnetic-Energy Regulation therapy on fatigue in patients with multiple sclerosis. *Altern. Ther. Health Med.* **17,** 22–8

8. Thomas J. Goodwin, P. D. & B., L. PHYSIOLOGICAL AND MOLECULAR GENETIC EFFECTS OF TIME-VARYING ELECTROMAGNETIC FIELDS ON HUMAN NEURONAL CELLS. *Sept. 2003 NASA/TP-2003-212054* at <http://ston.jsc.nasa.gov/collections/TRS/_techrep/TP-2003-212054.pdf>

Living Awareness

Our group has been approached by Robin Moore, who teaches Meditation and Mindfulness. He is available for private one-on-one lessons and has offered to do a talk for our group.

'Living Awareness' was conceived by Robin Moore in 2010 with the aim of demystifying meditation practice and bringing it into the mainstream, particularly in health and educational settings.

Robin has been practicing meditation since his late teens and noticing the tremendous benefits in his own life, was inspired to teach it to help others. This led to the creation of 'Living Awareness', and initiating the provision of meditation classes in local health centres which specialise in complementary therapies for anyone affected by cancer.

Robin currently offers 'Living Awareness' classes at 'South East Cancer Health Centre' and volunteers at a well-known London hospital specialising in cancer.

Robin has: given talks at Nescott College in Surrey for student health workers; leads walking meditation groups for local people near his home town of Epsom, Surrey; and works as a volunteer for 'Fishability' which supports ex-military personnel suffering from Post Traumatic Stress Disorder (PTSD).

Meditation and Mindfulness

When many people think of meditation, they imagine sitting in uncomfortable cross-legged poses, eyes closed. arms resting on the knees, thumb and index fingers joined, chanting 'Om Om!' That is enough to put many people off from the start, and let's face it, it can make you feel a bit silly.

The best description of meditation I have found was written by a good friend of mine in the United States, Tom Thompson, of the Awakened Heart Centre for Conscious Living:

> "Meditation is simply resting as effortless, choiceless, silent awareness. Resting means meditation is not difficult or complex, it is a natural, effortless way of being. Resting means you are not attempting to change or accomplish anything. You are simply resting, allowing everything to be as it is. Effortless means you are not trying to be anything or anyone, nor make anything happen or not happen. You accept and welcome everything as it is, including yourself and your thoughts, feelings and experiences. Choiceless means there is nothing to figure out, resting in silence and aware of everything and nothing."

Two types of meditation are taught: a formal sitting meditation and mindfulness meditation. Mindfulness meditation can be practiced anywhere at all; at work, walking, eating and even in a busy city centre. When used together, these meditation practices can produce amazing results, increasing both well-being and inner peace.

Meditation groups

Groups consist of 6 weekly 1.5 hour sessions and include formal sitting, usually in chairs provided, and group discussions. Cost £10.00 per person per week. Group size depends upon the site and hall being used. Please contact me for a current schedule as new groups are starting all the time.

Private sessions

One to one private sessions are available and are carried out in the comfort of your own home or garden. Private sessions are recommended if you need time to explore any personal issues in more detail or prefer not to be in a group setting. An initial 2 hour consultation is required and thereafter 1.5 hour sessions are recommended. Cost: £35.00 per hour dependent on location.

Couples Meditation
To allow someone to simply be who they are is one of the greatest gifts you can offer them. Meditation with someone you love and practicing mindfulness together is simply wonderful. It can bring space-which in turn allows love to flourish. A 2 hour initial consultation is required, thereafter 1.5 hour sessions are recommended. Cost: £40.00 per couple, per hour, dependent upon location.

Zazen Meditation
This form of meditation is the classical Zen meditation often practiced in Zen monasteries. It is my personal choice of formal practice. Zazen is not ideally suited for someone new to meditation as it requires a fair bit of discipline, but would be well suited for someone who has been meditating for a while and who wishes to deepen their practice. 1.5 hour sessions available and I can provide a Zafu (cushion). Cost: £35.00 dependent upon location.

Benefits
The benefits of regular practice are numerous, here are just a few:

- Release of general tension and anxiety
- Enhances the Immune system
- Increases energy strength and vigour
- Drop in cholesterol levels and risk of cardiovascular disease
- Decreases respiratory rate
- Prevented, slowed or controlled pain of chronic illness
- Reduced need for medical care

Mindfulness practice has become very trendy and has now found its way into mainstream psychotherapy, counselling and some NHS hospitals. In the United States it has been championed by Professor Jon Kabat-Zinn for many years, having great success in treating a wide range of physical and emotional issues, and more recently by Eckhart Tolle, the bestselling author of 'The Power of Now'. Mindfulness practice was originally a Buddhist practice but has found a very important role in our busy modern lives. In conjunction with formal sitting meditation it can quite literally be life changing.

The list of benefits with daily mindfulness:

- Builds self confidence
- Increased emotional stability
- Improved relationships
- Increased productivity
- Able to see a larger picture in a situation
- Mind ages at a slower rate
- Helps with focus and concentration
- Increases listening skills and empathy
- Provides peace of mind and happiness
- Deeper understanding of yourself and others

Contact details
Robin Moore
Mobile: 07931 950502
Home: 01372 209144
Email: mindfulness66@hotmail.co.uk

If you would be interested in attending a talk by Robin, for our ME/CFS group, please let us know by emailing us at: guildfordME@hotmail.co.uk

Gut bugs misbehaving? The microbiome and ME/CFS

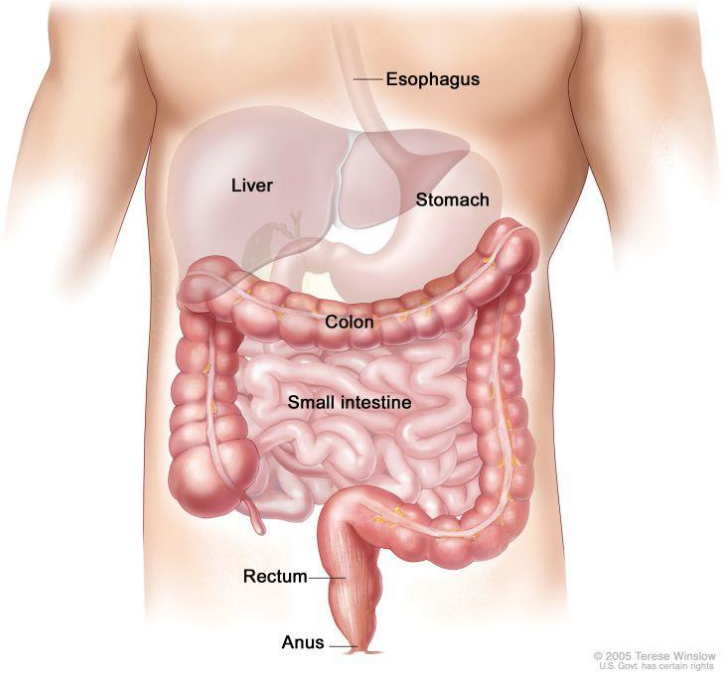
Source: http://phoenixrising.me/archives/20926
By Simon McGrath

Bugs are not all bad, in fact many in our gut are essential to good health, but problems with these could help explain some diseases, possibly even ME/CFS. Simon McGrath takes an introductory look at the Microbiome – an area that is fast becoming a focus for several research teams looking at our own illness…

The microbiome – the bugs that live in our gut and on our skin – has become a hot topic, not least because of the coverage of 'faecal transplants' that apparently cure life-threatening infections by restoring the microbiome with poop from healthy donors.

There are some impressive stats around: with 100 trillion cells microbes outnumber our cells around 10:1 and there are around 5 million different gut microbe genes compared with around 25,000 human ones.

If it's any consolation, we are 98%+ human by weight – since the microbes are tiny – but it's probably more accurate to think of ourselves as mobile ecosystems rather than as pure human beings.



Home for gut microbes; few survive in the stomach but they flourish in the small intestine and dominate the colon – 60% of the dry weight of poop is bacteria.

> "I think that the microbiome is going to be where the action is"
>
> *Ian Lipkin**

But what's this all got to do with ME/CFS? Well, Ian Lipkin and others think microbiome problems could be behind the chronic inflammation that is often linked to our illness, and which may even be revealed as a cause of the disease.

Peering into the microbiome

The microbiome refers to all the microbes in our gut and on our body: bacteria, fungi and single cell organisms (and even viruses). Technically, the microbiome refers to the collective genes of all the microbes (microbi*ome* as in gen*ome*) while the microbes themselves are known as the microbiota, which is the term I'll use here.

The microbiota isn't just applicable to the gut but can apply all over our bodies: armpits, mouth, nose, skin and more. However, most research and this article will focus on the gut microbiota – the biggest and most important area.

***W. Ian Lipkin, M.D., is the John Snow Professor of Epidemiology and Professor of Neurology and Pathology at Columbia University, Director of the Center for Infection and Immunity at the Northeast Biodefense Center, and member of the WHO Collaborating Centre on Diagnostics, Surveillance and Immunotherapeutics for Emerging Infectious and Zoonotic Diseases.**

We tend to think of microbes as nasty thing to be avoided, but the microbiota is surprisingly useful and probably essential to our survival, for reasons that include:

- making nutrients available, including making K and B vitamins
- helping protect us from disease by 'crowding out' harmful pathogens, much like a densely-planted garden border stops weeds from growing
- helping our immune system develop properly

So it's perhaps not surprising the microbiota is now being called 'the forgotten organ'. Like any organ it can malfunction and microbiota problems are increasingly being linked to diseases, including Inflammatory Bowel Disease and Type 2 Diabetes.

The good, the bad, and the somewhere in-between

Thousands of different species can survive and thrive in the human microbiota, but most of us carry around 500 species. Our individual microbiotat normally remains stable over time, though each person's is distinct; even identical twins have different microbiota.

While there are many, many species of bacteria, in some way they play only a few different roles. The good guys are called 'symbionts', clearly paying their way e.g. those that make B vitamins and vitamin K.

The bad guys – the pathogens like cholera and amoebic dysentery – aren't really part of the microbiota at all. Neutral 'commensals' don't do anything directly good but don't harm us either, and may well help by simply crowding the unhelpful types, especially the 'pathobionts'. Actually, as well as 'crowding-out', some bacteria fight each other with lethal proteins.

'Pathobionts' include the infamous superbugClostridium Difficile (C. diff for short) that usually sits there harmlessly in small numbers. However, in some situations – such as when helpful and neutral bacteria have been decimated by antibiotics, pathobionts show their Dark Side e.g. C. diff can take over causing bloody diarrhoea, which can be fatal in people already in poor health – and this is why C. diffcan be so deadly in hospitals.

How do we know?

The upsurge in microbiota research is driven by new tools to study it. The traditional way of identifying bacteria is to grow them in the lab until there are enough to study properly – but only 1% of gut microbes will grow in lab conditions, making the microbiota a black box til now. However, new sequencing technology means bacteria can be detected by their DNA (and RNA) and in minute quantities, without the need to grow it first. There are two main techniques:

16S ribosomal RNA sequencing: like us, bacteria have ribosome that make proteins, and the RNA of the ribosome is unique to each species – a handy fingerprint for identification.

Full sequencing. A more difficult and expensive but more comprehensive approach is to sequence everything in the microbiome, to reveal every gene (5 million of them), giving a window on what the microbiota actually does and how it might interact with us. The full sequencing approach is also thought to give a more robust measure of the bacteria present and their relative quantities.

Microbiota and our immune systems

More immune cells are in the gut than anywhere else in the body, which makes sense as that's where most bugs are too. But it isn't simply bugs and our immune system facing off against each other: it turns out that the immune system needs the microbiota both to develop normally and to keep to keep it on an even keel. Germ-free mice, raised in sterile conditions, have no microbiota and are prone to some gut inflammatory diseases. This seems to be linked to problems with gut immune cells – particularly regulatory T cells (T-regs, shown in the photo), which we know don't develop properly in germ-free mice. T-regs help keep the immune system from over-reacting and setting off chronic inflammation; in particular they quieten down T-helper cells that otherwise rev up the immune system.

Out of balance
Dysbiosis is the fancy term for the gut bacteria getting out of balance, particularly the relationship with 'pathobionts', those bacteria that are harmless enough in small doses but can wreak havoc if given their head. The diagram opposite shows how an imbalance can lead to inflammation, which is what seems to be happening in Inflammatory Bowel Disease (IBD): for some reason there aren't enough of the symbionts that produce key molecules that help regulate the immune system, and inflammation results. There is also evidence in IBD that the body produces antibodies against helpful 'commensal' bacteria, and killing off the commensals would help the harmful pathobionts flourish.

Maybe, just maybe, microbiota problems are also behind the low levels of chronic inflammation and other immune dysfunction that is often seen in ME/CFS.

Cause or effect?
The central question in microbiota research is not are microbiota changes associated with diseases (they are in numerous cases)? But are the changes a cause of disease or simply a knock-on effect? The findings above for Inflammatory Bowel Disease suggest a causal role for microbiota, and the success of faecal transplant treatment for C. diff (see box) is the strongest evidence yet.

And there are also examples of a causal relationship between microbiota and more complex illnesses. The best known case is obesity in mice. Germ-free mice, raised in sterile conditions, have no microbiota and tend to be thinner than normal laboratory mice. One possible reason for this is that the gut microbiota break down complex carbohydrates that mice can't digest on their own, making more food available.

When these germ-free mice are given microbiota from lean mice they put on some weight, but they put on much more weight when given bacteria from obese mice. So perhaps one factor behind obesity is that some people have microbiota that help them extract more energy from food, and so put on more weight.

However, it is early days for such research and the relationship between disease and changes in microbiota remains uncertain.

Microbiota and ME/CFS
Gastrointestinal symptoms are common in ME/CFS and could be linked to microbiota problems, and even chronic inflammation. Research on the microbiota is just beginning to appear in the ME/CFS literature:

Faecal transplants: Hard to swallow

The microbiota's big break in medicine was the faecal transplant to treat persistent infections – such a gross idea that the media could not resist covering it (or us resist reading it). Of course, gross is relative – patients suffering with intractable or even life-threatening C difficile infections often don't see it that way: "Because a fecal transplant is gross, but cramps and bloody diarrhea are aesthetically pleasing?", as one writer put it.

Initially the reports of faecal transplant were simply anecdotal and I have to admit I thought it all sounded like woo science. Then came case studies and asystematic review of 317 cases found a 92% success rate. Finally a trial comparing faecal transplant against antibiotics for treating recurrent C. diff was stopped early because the faecal transplant was so much more effective than the antibiotic. Faecal transplants are entering the mainstream, but fortunately someone has just found a way to extract the bacteria from faeces and parcel them up in asimple pill: yum.

- Professor Kenny De Meirlier's small 2013 study on the microbiota of patients from Norway and Belgium had mixed results with differences seen between Norwegian patients but not between Belgian patients and controls.
- A recent paper details 60 CFS cases treated (in the 1990s) with colonic 'bacteriotherapy' and reported a 58% rate for "resolution of CFS symptoms", though it wasn't clear how the study measured outcomes.

- Pilot results from a CAA-funded microbiome study by Dr Shukla indicated that the microbiome of CFS patients responds differently to exercise than healthy controls. Data from the full study is now being analysed.

Two important new microbiome studies underway

> **Invest in ME** have raised £100,000 (wow) for a microbiome study aiming to establish 'whether microbe-driven inflammatory responses can provide an explanation for the pathophysiology of ME'. The study, run by the impressive Professors Tom Wileman at the University of East Anglia and Simon Carding at Norwich, began last October as a three-year studentship and initial results could emerge in 2015. They will be looking at the microbiota of ME patients including both bacteria and viruses, testing for leaky gut and using metabolomics to look at the metabolism of the whole microbiota.
>
> **Professor Ian Lipkin** is focused on the microbiota for the same reason, particularly because his latest study found evidence of abnormal immune response in ME/CFS patients – could the microbiota be the cause? A microbiome study is underway, run by Mady Hornig at his lab: they plan to use a CFI cohort of 50 patients and 50 carefully-matched controls, but the study is held up by a lack of funds because the work they want to do is very expensive.
>
> … it is probably inappropriate for me to be passing the hat, but that's precisely what I am doing.
>
> If you want to make a donation of funds direct to this study, you can do so here. The team would also like to look at blood samples as well as the microbiome, but have yet to secure funding for this work. There will hopefully be a Phoenix Rising interview with Ian Lipkin about his microbiome project coming very soon, so do stay tuned.

It may seem strange that bugs in our guts – not specific bugs, but an imbalance between different types – could cause ME/CFS, but that's just the line of research that Invest in ME and Lipkin are pursuing, focusing on a possible link with chronic inflammation. Microbiota in ME/CFS research is now taking off, and patients are helping make it happen.

A study into muscle dysfunction at Newcastle University

Source: http://phoenixrising.me/archives/20781

In May 2012, Action for ME awarded £25,000* to Dr Phil Manning and Prof Julia Newton at Newcastle University for their study, Understanding muscle dysfunction in ME/CFS: developing a drug pre-testing system.

The funding provided by Action for ME will be matched by Newcastle University's Faculty of Medical Sciences to establish the Action for M.E. PhD Studentship. A top science graduate, Gina Rutherford, is being trained and employed to work on this study over three years.

People with ME/CFS frequently describe a sense of muscle-energy depletion after exercise, often accompanied by muscle pain. Previous research has shown that, on exercise, almost 50% of patients over-deplete the energy within their muscle and switch into 'anaerobic' metabolism.

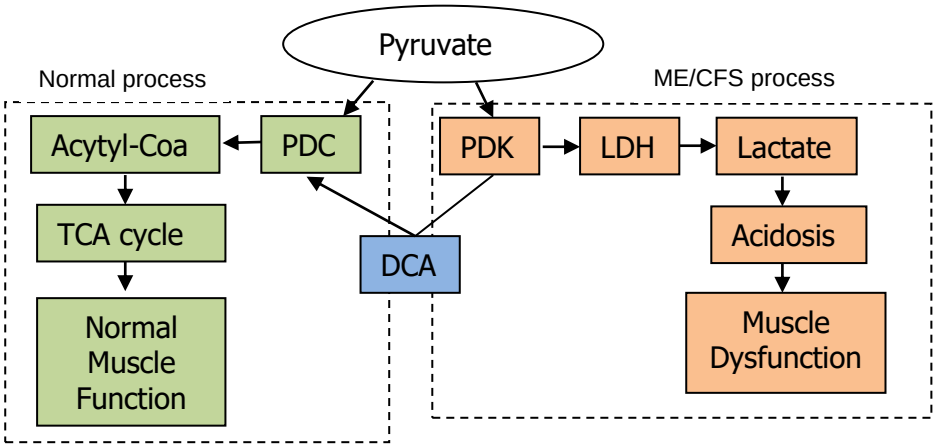
This study will use state-of-the-art techniques to grow muscle cells in the laboratory and measure metabolism of these cells. It will explore why muscle cells from ME/CFS patients have problems with muscle energetics and why they switch their pathway of energy generation. This will help us understand why this makes them fatigued and how we can improve this to reduce fatigue.

Development of this laboratory system will also provide an experimental system to allow us to test drugs potentially able to treat fatigue and alter metabolism in ME/CFS.

A recent (December 2013) presentation given by Gina Rutherford explained that findings show significantly elevated muscle acidosis in ME/CFS patients following exercise. And that the same ME/CFS patients took a prolonged time to recover from the acidosis. The acidosis being a build-up of Lactic Acid as consequence of impaired PDC (Pyruvate dehydrogenase complex) function.

Impaired PDC function
Our cells require glucose from our food for the creation of energy. But before energy can be created the glucose must be converted to pyruvate and then into Acetyl-CoA.

It is the PDC function that is responsible for converting the pyruvate into Acetyl-CoA.



The diagram on the previous page shows in green the normal process of the conversion of Pyruvate into energy for muscle function. In red the ME/CFS process that leads to a build-up of lactic acid and muscle dysfunction.

For an ME/CFS patient PDK interrupts the normal PDC part of the process. Because the medication DCA can block PDK it may prove to be an effective treatment for ME/CFS patients.

For further information please refer to the following internet address:
www.youtube.com/watch?v=dsBQ4t_gcGM

For further information about Action for ME research please refer to the following link:
http://phoenixrising.me/archives/20781

For further information about other current research into ME/CFS please refer to the following link: www.cortjohnson.org/blog/2014/01/28/whats-2014-look-ahead-chronic-fatigue-syndrome

---

Liposomal B12

Vitamin B12 has long been famous as a key supplement for ME/CFS. But it's a difficult supplement to absorb therefore injections have been required to achieve a meaningful dose. Now injection level B12 can be achieved with a home supplement in the form of a spray for under the tongue. This is made possible by encapsulating the B12 in to microscopic fatty packages that survive the digestive system and then deliver the B12 inside the cells of the body.

A video explaining the concept is at this link: www.youtube.com/watch?v=VuDd2ylDPxc

The main benefits for ME/CFS sufferers being improved energy and mental clarity.

High dose B12 such as found in liposomal B12 is not well tolerated by all ME/CFS sufferers however. As such, it may be sensible to first try a low dose B12 supplement. Some ME sufferers who have anxiety as an issue have found that B12 can cause anxiety.

An example low dose B12 supplement and an example high dose liposomal B12 spray are shown below.

An example low dose B12 supplement
Jarrow Methylcobalamin B12, 1000mcg, 100 Lemon Flavour Vegan Lozenges

From Amazon UK for £9.90 with a free delivery option.

An example high dose liposomal B12 spray
Liposomal Methyl B12 Spray (MB12) – Readisorb. (500mcg Methylcobalamin per spray).

From Amazon UK for £22.99

Over 90% absorption of B12 (Methylcobalamin). The only liposomal methyl B12 supplement available. Get almost the same bioavailability as the injections, without the pain! "Vitamin B12" refers to a group of compounds known as cobalamins. The most common form of vitamin B12 is called "cyanocobalamin." Vitamin B12 in the brain and central nervous system is only present as methylcobalamin, which is why methylcobalamin is the form of vitamin B12 that is called "neurologically active." Your liver has to transform regular vitamin B12 (cyanocobalamin) into methylcobalamin. Vitamin B12 in its active form, methylcobalamin, may give a much better result than other forms which have to be converted into methylcobalamin.* This is a Liposomal complex liposomes surround the Mathylcoblamin to ensure bioavailability. Ingredients One spray has 500 mcg of Methylcobalamin.

The Guildford & West Surrey ME/CFS Group newsletters aim to inform members of relevant news and treatment options. Use of the treatments is done at your own risk.