Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Winter 2012

Future dates

The following ME meetings are open to all members and carers.
Please put these dates in your calendar.

21st March 2013 (Thursday) 4pm The Seahorse
The Street, Shalford, Guildford, GU4 8BU

8th April 2013 (Monday) 7.30pm Worplesdon Hotel
Perry Hill, Worplesdon, Guildford GU3 3RY

23rd May 2013 (Thursday) 12 noon The White Hart Pub
White Hart Lane, Wood Street Village, Guildford, Surrey, GU3 3DZ

Because of the high prices of the Holiday Inn we are trying the White Hart as an alternative morning meeting venue. However, the opening time is 12 noon.

Although mostly setup with restaurant style seating there is a bar area with comfortable seating. Prices are reasonable and the food is very good.

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.

25th June 2013 (Tuesday) 3pm The Albany
80 Sydenham Road, Guildford, Surrey, GU1 3SA

There are 2 car parks on Sydenham Road 200yds from The Albany
and there are parking bays directly opposite

Important discovery exposes autoimmune nature of ME/CFS – HERVs implicated

by Joel (Snowathlete) Feb 20th 2013
Source: http://phoenixrising.me/archives/16017

Some dates you remember forever. Yesterday, on Wednesday 20th February 2013, a paper was published that may represent a major breakthrough in understanding the underlying mechanisms and cause of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

The paper, from long-time ME/CFS researchers Dr Kenny De Meirleir, Vincent Lombardi and other colleagues in association with the Whittemore Peterson Institute, reports findings that amount to ME being an autoimmune disease.

Dr Kenny De Meirleir is perhaps best known for the work he has done on the gut and its link to the pathophysiology of ME/CFS, so it is no surprise to hear that this latest finding is related to the major role of the lymphatic immune system in the gut. What will surprise some is that they have been able – despite its massive complexity – to narrow it down to a specific type of cell and to show how this cell ends up creating a state of autoimmunity in the body.

Prompted by reports of associations between other neuroinflammatory diseases and Human Endogenous Retrovirus (HERV) expression, De Meirleir and his team looked for the same type of occurrence in ME/CFS patients. Specifically, they looked in tissue from duodenum biopsies – the duodenum is at the top of the small intestine.

What is being reported?
The paper reports that the Plasmacytoid dendritic cells (pDCs) of eight out of 12 ME/CFS patients studied were found to be immunoreactive to antibodies against HERV proteins. In contrast no immunoreactivity was found in any of the eight controls.

All patients met both the Canadian and Fukuda criteria and were found to have substantial disruption of gut microbiota. Samples were from surplus de-identified clinical biopsies from previous ME patients.

pDCs are part of the innate immune system. They circulate in the blood but occur mostly within the secondary lyphoid organs, which is why they are present in the gut. pDCs are antigen-presenting cells that have a stimulatory role within the immune system. This immunoreactivity to HERV proteins was found uniquely in these pDC cells only. Dendritic cells have the potential to mistakenly identify something as an antigen when they shouldn't, and this may be the cause of some autoimmunity.

HERVs are in our genome. We were born with them, and they are left over viral elements from ancient retroviruses that infected our ancestors' germ line cells millions of years ago and stayed there passively, being replicated and passed on to new generations. They are abundant in our genome (5-8% – Robert Belshaw et al, 2004), but most, probably all, are defective due to mutations and deletions that have occurred in our genome over the millennia. Unlike exogenous retroviruses such as HIV, HERVs are replication incompetent – so they're not a moving target. Our understanding of HERVS is still undergoing change, and there is some evidence that some of this DNA – once thought to be nothing more than junk – actually contributes to our existence by performing various useful tasks within us (J-L Blond et al, 2000). It is known that these HERV elements in our DNA can and do express proteins, though normally they do not provoke a significant immune reaction.

The study reports that proteins found in the ME samples reacted with monoclonal antibodies to HERV proteins and that the immunoreactive cells were pDCs.

What checks did they make?
Positively, having found that the ME patient duoednum tissue was reacting to these HERV antibodies, De Meirleir and his team went a step further and checked to see whether murine retroviral antibodies would also cross react with the tissue – something which should occur if HERV proteins were present – and the results were again positive.

Finally, the team carried out further checks to rule out non-specific reaction and also tested stomach tissue from the same patients and controls, all of which came back negative, as expected.

Now they made efforts to determine exactly which cell types were immunoreactive to the HERV protein antibodies. Via a series of further tests the team hoped to whittle down the potential cell types. First they managed to zoom in on the hematopoietic cell lineage and then further sharpened the result to identify the cells as pDCs. They then double checked via a secondary means to confirm the result.

Having identified that the cells were pDCs, next they counted them and compared that count to the healthy controls. The ME patients were found to have approximately 4.7 times as many pDCs as the controls. Of the pDCs in the duodenum samples from ME patients, approximately 44 percent were found to be reactive to the HERV proteins.

Furthermore, in order to confirm that this was definitely a reaction to identifiable HERV proteins, the team sequenced both the RNA derived from the biopsy samples and from purified pDCs and found matching sequences from known HERVs. Although at this point they cannot definitively rule out that the immunoreaction seen was a result of an infectious exogenous retrovirus, as opposed to a HERV, their identification of matching HERV sequences argues strongly against this possibility.

So the cause of ME/CFS might be autoimmunity to HERVs?
As De Meirleir and his team point out, this would be the first time that an association between pDCs and HERVs has been shown to cause disease, though proven autoimmune diseases such as Multiple Sclerosis and Rheumatoid Arthritis have already been linked with pDC abnormalities and HERV involvement (G Freimanis et al).

The discussion section of the paper suggests that a number of immunological measurements reported in ME/CFS patients in the past, by various groups, may be a result of HERV involvement in pDCs, because pDCs are known to produce a variety of other immunological cells in abundance, such as interferon alpha, which modulates Natural Killer cell (NK) function. Low NK cell function is often associated with ME/CFS (Whiteside TL et al, 1998).

A lot is still unknown about HERVs, but they have been increasingly linked with disease. A study looking at HIV found that HERV expressed peptides were higher in HIV positive patients compared to controls and that T cells responded to these peptides (K E Garrison et al). A pair of studies looking at EBV showed that it could potentially activate retroviral elements in our DNA (Sutkowski et al, 2004 and 1996) and it's possible that something similar could be going on here. Indeed the authors of this paper mention this previous finding and point out the long association between the disease and Herpes viruses, including De Meirleir's previous discovery of herpes viruses in the duodenum of patients with ME/CFS (De Meirleir et al, 2009).

For most of us, immune dysfunction is a hallmark of ME/CFS, and several papers have reported specific immune dysfunction in the disease, particularly in the gut, highlighting the important role that the gut plays in maintaining health. For example, changes in the gut flora can result in incorrect function of the gut mucosal barrier (Shaheen E Lakham et al, 2010). Without these components of the immune system in our gut being correct, we are exposed to increased infection and inflammation and it is thought that this inflammation may be an aggravating factor as there is some evidence of inflammation increasing HERV protein expression and autoimmunity (Lee YK et al, 2011).

What next?
Replication. That's what someone (we don't know who yet) needs to do; someone has to replicate and confirm these findings in a bigger sample of patients. Or disprove them…

We know from experience that we mustn't get ahead of ourselves, and following replication comes more study because it would need to be confirmed that this was the cause of ME/CFS and not some knock-on effect unlinked to the pathogenesis of the disease, but if it checks out then we have a confirmed autoimmune disease and the certainty that goes with it.

We don't understand autoimmune diseases that well yet, though this finding has the potential to revolutionize our understanding of autoimmunity. If confirmed then these findings could have repercussions for several other autoimmune diseases, particularly those with gastrointestinal dysfunction and neuroinflammation, such as MS, Lupus, and Crohn's, whose cause may follow the same or a similar model. That would be good for everyone. Once again it seems ME/CFS has become sexy, just like it was when the XMRV saga began. Let's hope this works out better in the long run…

If this research stands up then we are in a great position, because we already understand quite a bit about where the problem is happening. The bad thing about HERVs is that they're immutable – they're in our DNA and we can't do much to change that. On the plus side, everyone has HERVs, so if they are linked with disease then it's important to get to the bottom of how and why, for everybody's sake.

Treatments for autoimmune diseases tend to be immune-modulating drugs to tone down the immune system's effect and limit damage, and initial 'treatment' may also involve reducing gut inflammation. The theory is that if you can cut inflammation then you should get less autoimmune reaction, though that alone would be unlikely to fix the problem.

It's too early to talk about fixes – the first thing we need is for someone to confirm these findings…until then, hold fire…

A reason to be hopeful
If it works out then this discovery will be a breakthrough in understanding the cause and mechanisms of ME/CFS. With that reality will come greater recognition, greater funding, greater focus, and ultimately – in the long run – treatments!

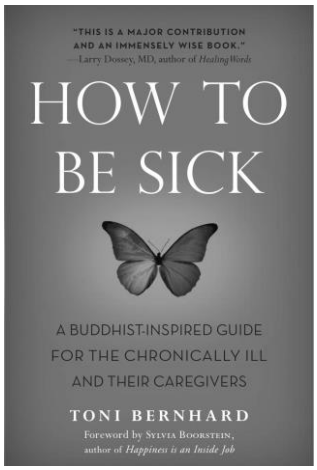
Of course none of this will happen overnight, we still have some way to go, but it could mean the beginning of the end, and we have waited for the end to this illness for so long. We deserve this to work out. Don't we?

But you don't always get what you deserve. Only time will tell if we remember Wednesday 20th February 2013 as a significant milestone on the long journey we are on to get to the bottom of this illness.

Joel was diagnosed with ME/CFS in 2009 but struggled with the illness for some time prior to this. He loves to write, and hopes to regain enough health to return to the career he loved and have his novels published.

A guide to living with chronic illness

A few of our members have mentioned a book that maybe of interest. It's called "How to be sick: a Buddhist-inspired guide for the chronically ill and their caregivers" by Toni Bernhard.



I fell ill on a trip to Paris in 2001 with what the doctors diagnosed as an acute viral infection, but I never recovered. I wrote this book while bed-bound – on my back, laptop on my stomach, notes strewn about on the blanket, printer within arm's reach. My goal in writing it was to help and inspire those who must meet the challenges posed by any chronic illness or condition: coping with the relentlessness of symptoms; weathering fear about the future; coming to terms with a life of relative isolation; facing the misunderstanding of others; dealing with the health care system; and, for a spouse, partner, or other caregiver, adapting to so many unexpected life changes.

One of our members, Tracy Rolfe has kindly offered the following insight into the book.
How to Be Sick is a Buddhist-inspired guide for the chronically ill, but you don't have to be a Buddhist to benefit from the wise and compassionate advice given in this book. The author, a law professor, developed ME following a viral infection in 2001, though the book could be equally useful for sufferers of other chronic diseases and their carers.

How to Be Sick is not about how to become sick but rather 'how to live a life of equanimity and joy despite physical and energetic limitations'. It aims to help the chronically ill and their care-givers cope with such challenges as living with on-going symptoms, coming to terms with a more isolated life, coping with fear about the future, facing misunderstanding from others and dealing with the health care system.

It covers many useful and interesting concepts. For example, the activities that bring us joy in life are also the ones that make our condition worse. This is difficult to adjust to. Bernhard suggests what she calls 'broken-glass practice'. The idea is to look at a glass and know that it is already broken in the sense that it is only a matter of time before someone or something destroys it. We can look at our bodies in the same way: everyone will decline or decay eventually, somehow or other, suddenly or gradually. This disease is simply the way that is happening for me, now. So everyone's life is impermanent and unpredictable. I am not, after all, unusual. Being aware that anything can happen at any time, helps us enjoy and appreciate what we can do and what life still has to offer us.

Bernhard goes further and explores positive things she can now enjoy because of her illness. She describes her newfound love of classical music, a pleasure she did not have before her illness. She discusses her heightened awareness of changing seasons, brought about by observing them through her bedroom window because of having to spend extended periods of time in bed.

In our culture, illness is seen as something to be fought and resisted, denied even. It is seen as a passing state from which we recover. Berhard's book encourages us to accept illness and suffering as part of life, a concept alien to the Western mind. This does not mean we should reject possible appropriate treatment should it become available (which one of us would not consider participating in a UK ampligen or rituximab trial?) but rather that acceptance is the first step to living a peaceful and perhaps even joyous life despite and within the confines of the illness that is, for now, part of our lives.

Endorsements – taken from the associated website: www.howtobesick.com
"Toni Bernhard offers a lifeline to those whose lives have been devastated by illness, and shows us all how to transform suffering into peace and even joy. A beautiful book filled with grace, humour, and humanity."

Lynn Royster, Director of The Chronic Illness Initiative at DePaul University

"A immensely wise book. Health psychology has been poisoned by the view that the best way to approach illness is through a muscular, militant resistance. This books shows otherwise. Bernhard reveals how letting go, surrendering, and putting the ego aside yield insights and fulfilment even in the presence of illness. This is a major contribution."

Larry Dossey, MD, author of Healing words

"Toni Bernhard's hard-won wisdom dealing with chronic illness teaches us how to be kind to ourselves, to counter negative thoughts about our life and our health, and to live fully in the present—neither regretting the past nor fearing the future. Who among us couldn't use these life-affirming skills? Bravo!"

Susan Milstrey Wells, author of A Delicate Balance: Living Successfully with Chronic Illness

amazon.co.uk

Available from Amazon.co.uk £9.11

Further information is available at the following internet link: www.howtobesick.com

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Prof Malcolm Hooper – the saga of science

Source: http://voicesfromtheshadowsfilm.co.uk/2012/prof-malcolm-hooper-the-saga-of-science-2-12-12/

On 2nd Dec 2012 the Independent on Sunday published a letter signed by 27 medical professionals — who may be described as supporters of the psychosocial model of ME/CFS — in which they refer to the harassment of some researchers working in the field.

It is regrettable that the wholly unacceptable actions of a few people have not only undermined the efforts of those who, for many years, have sought to engage scientifically with proponents of the psychosocial model but have tarnished the reputation of all ME/CFS sufferers. Further, it has allowed a narrative to develop, namely that ME/CFS patients are prejudiced against psychiatry and are resistant to the possible role of psychological factors in their illness. A siege-like mentality has developed between patients and doctors and it is essential, if progress is to be made, to move beyond this impasse towards a constructive dialogue based on evidence, so that if the psychosocial model is found wanting, a commitment can be made to look for alternative causal mechanisms.

Much of the recent frustration has stemmed from the presentation of PACE Trial data in The Lancet (published online February 18 2011) and other journals. For example, in their accompanying editorial in The Lancet, Bleijenberg and Knoop wrote: "PACE used a strict criterion for recovery…In accordance with this criterion, the recovery rate of cognitive behaviour therapy and graded exercise therapy was about 30%", with another journal reporting "a recovery rate of 30-40%" (BMC Health Serv Res. 2011; 11: 217, three of the authors being signatories to the letter to the Independent on Sunday).

Both these reports are wrong, because no recovery data from the trial have been published, and although The Lancet's senior editor, Zoe Mullan, acknowledged this error and promised to publish a correction, to date (22 months after publication) no correction has been issued, allowing this misrepresentation to continue.

The above are but two of many well documented discrepancies surrounding the publication of selective results of the PACE Trial.

In their letter, the signatories say that the harassment: "risks undermining research, preventing the development of new treatments and discouraging specialist clinicians from entering the field. We fear that this may have resulted in patients not receiving the best treatments or care".

Quite apart from the fact that the signatories' favoured treatment may not be the best for people with ME/CFS, the signatories make no distinction between "extremists" and those who continue to present reasoned, evidence-based critiques of the psychosocial model. Moreover, they appear to have conflated criticism of a particular psychiatric theory with the wholesale rejection of psychiatry per se: being critical of certain psychiatrists' beliefs about the causation of ME/CFS is not the same as being anti-psychiatry.

The psychosocial model has been subject to challenge because when its predictions were tested empirically, such as in the FINE and PACE Trials, objective data from these trials show clearly that ME/CFS is not perpetuated by dysfunctional thinking and deconditioning as the model posits.

People are angry, but that's because a small group of psychiatrists who have consumed such a large share of research funding for twenty years have acted in a way that is perceived to be wholly unscientific ie. when the evidence (even from their own studies) shows their ideas to be wrong, they either ignore the evidence (eg. FINE), or appear to misrepresent it (eg. PACE), and the system which is meant to protect against this – academic peer review - has completely failed to prevent the dissemination of papers which contain egregious errors.

It is also the case that many patients and clinicians alike feel let down by the wider scientific community for not speaking out against apparent abuses of process such as the post hoc revision of primary outcome measures in the PACE Trial which made it possible for a participant to deteriorate after treatment but still be described as "recovered". Had such a situation applied in a drug trial there would, rightly, have been an outcry.

For the proponents of the psychosocial model to continue to ignore the biomedical evidence from world-class experts such as Drs Nancy Klimas, Mary Ann Fletcher, Anthony Komaroff, Kathy and Alan Light and Dan Peterson must surely conflict with a clinician's first duty to patients, as rejection of that evidence may carry the risk of iatrogenic harm.

As Professor Komaroff wrote in Nature Reviews Neuroscience, September 2011:
"Many of the documented abnormalities involve the central and autonomic nervous systems. In my experience, most sceptics are unaware of the extensive literature citing such abnormalities and become less sceptical upon reading it".

Professor Klimas was equally clear about those who dismiss the biomedical evidence, saying at the IACFSME Conference in September 2011: "Look at the studies of many patients – and they tell you the same. It is not difficult. I mean immune findings in ME / CFS is proved. It is not controversial, and it is not just a hypothesis. There is immune activation, it is dysfunctional cells and a significant degree of malfunction of the immune system….I have no difficulty (saying) with great certainty that the immune system in ME/CFS is not working as it should".

Given the well-established body of biomedical evidence and the failure of CBT and GET to produce objective benefits, people diagnosed with ME/CFS (and the clinicians who support them) struggle to comprehend the continued propagation of the doctrine that they can be cured and be returned to employment by psychotherapy, when the evidence from the psychosocial studies shows this is not the case.

It is time for a more productive dialectic so that patients can receive treatment and support based on sound evidence and researchers can work without fear.

Book: why we're not benefit scroungers

Stephanie Benstead is 23 years old and writes a blog and on twitter under the name Aida Aleksia.

She read Natural Sciences at Cambridge and started a PhD there but had to leave when she developed ME in early 2011. As a consequence of her illness, Aida started researching the adequacy of provision for disabled and chronically ill people in Great Britain. This led to her writing this book, in the hope that it would allow the non-disabled community to easily access correct information about disability, chronic illness and the welfare system.

It provides a bomb-proof argument against the idea of benefit fraud and a wilful sickness culture, a damning indictment of the processes used by governments to identify those who should be receiving help, and sobering tales of ordinary people's struggles against the kind of illness that could strike any one of us.

Benefit Britain?

The government is implementing major changes to the benefits system. Polls suggest there is public support for cuts and increased rigour in the system. But these views may be based on misinformation. Disabled author Stephanie Benstead wrote her book Why We're Not Benefit Scroungers to address some of these issues.

The book starts with a discussion of the welfare system in relation to the chronically ill and disabled. Misinformation, rhetoric and prejudice are addressed and countered by reference to facts, figures and reports from organisations including the DWP, Joseph Rowntree Foundation and Citizen's Advice Bureau.

Life in the slow lane

The second, and larger, part of the book brings together ten stories from people with a range of illnesses and disabilities. Their stories show the many difficulties that chronically ill and disabled people still face. These include poor education as a direct result of disability or illness, illnesses made worse by the stress induced by the benefits system, cost-cutting exercises causing deterioration in health and the life-changing effects of unexpected illness.

Why We're Not Benefit Scroungers provides an insight into the lives of the chronically ill and disabled, and the realities of what they face in the welfare system. Misinformation from the government has allowed many members of the public to adopt an attitude of resentment and animosity to these people.

But the data show a different story – one of sick people terrified of receiving brown envelopes; of people suffering deterioration in health after being told they are or soon will be fit for work; a story of people living in poverty and fear.

Stephanie Benstead – writing as Aida Aleksia - gives detailed consideration to the problems besetting the controversial Work Capability Assessment for Employment and Support Allowance, and why these cause so much distress amongst the disabled community. Disability Living Allowance, together with its soon-to-be successor, Personal Independence Payments, is discussed in light of what disabled people need and how this compares to what they get. The book concludes with suggestions on what a benefits system that works might look like.

Price, ordering and more information

The books costs £4.50 for print copy, £1 for pdf and can be ordered from the following website, which also includes further information: www.aidaaleksia.com

The 2012 Invest in ME conference on DVD

The price per DVD set is £12 and includes delivery to the UK.

Pay by Cheque
Send a cheque for £12 to -

Invest in ME
PO BOX 561
Eastleigh SO50 0GQ
Hampshire
UK

Please supply your name and address (and email address if possible). In addition, please mark your order with "PAL" which indicates the version suitable for UK DVD players.

Cheques should be made payable to **Invest in ME**

Online payment
Ordering and payment can be done online at the following link:

http://investinme.org/IiME%20Conference%202012/IiME%20International%20ME%20Conference%202012%20DVD%20Orders.htm

An overview of the 2012 Invest in ME conference

An overview of the conference can be found at the following website link.
http://investinme.org/Documents/MECFS%20Conference%202012/Ros%20Vallings%20IIMEC7%20Report.pdf

The information is very medically technical.

The 2013 Invest in ME conference (IIMEC8)

The 8th Invest in ME conference will be held on the 31st May 2013 in Westminster, London. An overview is included below. Further information can be found at the following internet link:
http://investinme.org/IiME%20Conference%202013/IIMEC8%20Home.html

Infection, Immunity and ME - mainstreaming ME research
Research into Myalgic Encephalomyelitis - specifically biomedical research into ME – has been receiving increasingly more attention from both major research institutes in several countries as well as national health organisations. The Medical Research Council (MRC) in the UK, the Food & Drug Administration and Centres for Disease Control and Prevention in USA have created initiatives for new biomedical research into ME. In Norway the Norwegian Health Directorate have allocated funding for biomedical research into ME following the 2011 double blind randomised clinical trial using Rituximab (Anti-CD20 monoclonal antibody) by Fluge et al (PLoS 6:10.Oct 2011) to successfully treat ME patients.

There is increasing research evidence of immune dysfunction in ME patients.
The UK MRC states -

"There is now preliminary evidence supporting the view that inflammatory mechanisms in the brain and spinal cord may underlie the pathophysiology of some severe disease CFS/ME phenotypes. Biobanks are now becoming available and create a unique opportunity for interrogation."

The IIMEC8 conference will show some of the major initiatives being taken to set up a collaborative strategy for biomedical research into ME to further this complex but exciting area of research leading to appropriate patient care and mainstreaming this field of research as well as this disease.

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.