Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Spring 2013

Future dates

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

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

17th July 2013 (Wednesday) 11am The Seahorse
The Street, Shalford, Guildford, GU4 8BU

25th July 2013 (Thursday) 7.30pm Worplesdon Hotel
Perry Hill, Worplesdon, Guildford GU3 3RY

7th August 2013 (Wednesday) 4pm 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.

20th August 2013 (Tuesday) 11am The Seahorse
The Street, Shalford, Guildford, GU4 8BU

5th September 2013 (Thursday) 7.30pm The Seahorse
The Street, Shalford, Guildford, GU4 8BU

Launch of inclusive UK CFS/ME Research Collaborative

April 30, 2013
by Simon McGrath
Source: http://phoenixrising.me/archives/16786

Monday, 22 April, saw the launch of the new UK Chronic Fatigue Syndrome/Myalgic Encephalitis Research Collaborative (CMRC). Set up by Stephen Holgate, MRC professor of immunology, and backed by the UK's main research funders (MRC, Wellcome Trust and NIHR) it aims "to create a step change in the amount and quality of research into chronic fatigue and ME". The launch featured some eye-catching provisional results that got good media coverage, particularly the study from Newcastle showing differences in lab-cultured muscle from CFS patients versus healthy controls. And an fMRI study found that patients had to use more brain regions to accomplish the same mental tasks as controls, confirming earlier work in this field.

Not everyone is happy
What's not to like? Well, although it's backed by most ME charities and almost all the UK's biomedical researchers, the collaborative is deliberately a broad church including all types of research, including psychological research. And that has upset a good number of patients.

The ME Association acknowledges these concerns, but its Chair Neil Riley argues:

> "The Research Collaborative is a big tent covering a wide range of views on causation, definition, epidemiology and management. We believe it is far better to be inside the tent discussing and debating these issues – as happened during the discussion session on Monday – than sitting outside where we would not have a voice. …Provided the Collaborative drives forward and promotes research into the biomedical causes of ME then we shall be in there, taking an active part and supporting its efforts. "

Action for ME, AYME, the Chronic Fatigue Syndrome Research Foundation, The ME Association and ME Research UK all agree. The most significant ME charity choosing to remain outside the tent for now is Invest in ME, who have voiced their scepticism, arguing that what's needed is exclusive focus on biomedical research.

Nonetheless, it was an extraordinary achievement to bring together such diverse views into a single collaborative. As Stephen Holgate says, "It is the first time this has ever been done anywhere in the world—to get buy-in from these different communities".

A new era of Research in the UK?
"a field that is in desperate need of new science"
- Stephen Holgate

For the last twenty years, the study of CFS in the UK has been dominated by researchers with a biopsychosocial perspective, so it's notable that the CMRC emphasises the need to do things differently. CFS is "a field that is in desperate need of new science", says Stephen Holgate.

At the meeting he highlighted several new areas and opportunities:

- The application of state-of-the-art research methodology, including Genomics, Proteomics and Metabolomics.
- Using the new Networks approach as powerful tools for integrating and modelling biological data. This systems-based medicine approach focuses on how biological systems interact within the body, rather than looking at changes in individual genes or proteins. Nancy Klimas's Neuro Immune Centre in Florida, with Gordon Broderick providing network modelling, is a great example of this.
- Emergence of large collections of biobanks. eg The UK ME-CFS Biobank and the CFI bio-bank in the States. Such well-characterised patient groups, with clinical and biological material, open the way to large-scale studies probing any number of biological mechanisms.
- Holgate also wants to engage a wide range of new fields such as maths and environmental science who could all add to the party.

This looks to me like an agenda for cutting-edge biomedical research, particularly as he says: By coming together in this way, the application of state-of-the-art research methodology… will greatly increase the chance of identifying pathways linked to disease causation and novel therapeutic targets.

As he's said repeatedly in recent years: "The key to success will be the engagement of scientists outside the field", drawing new blood into CFS research, bringing insights from other diseases, and encouraging young new researchers to study ME/CFS. Similarly, the MRC stresses the importance of proposals for research funding to include at least some researchers new to the field. And the MRC, who were at the launch, has a highlight notice encouraging specific biomedical areas, including neuropathology and immune dysregulation.

One other important area discussed was heterogeneity and case definitions, which is a big issue for the whole field. Stephen Holgate referred to CFS/ME as a 'complex group of conditions' ie multiple conditions with different aetiologies, and so 'phenotyping' – dividing patients into different groups on the basis of clinical information, or even biomarkers – is a priority too.

How will the new Research Collaborative make a difference?
It's still very early days for the research collaborative and the organisers hope that many new researchers will join the CMRC and help shape its future. However, it's already been agreed that there will be quarterly meetings between researchers and funding charities, divided into four different streams. The content of those streams will be decided at the first meeting of the CMRC on May 22nd. This meeting will also firm up research priorities, and a fundraising drive will be on the agenda too. An annual CMRC science conference is also possible, but with such a new organisation, much remains to be decided.

Stephen Holgate knows that some patients will continue to doubt the value of the new Collaborative, and anything he says is unlikely to change their minds. However, he hopes that the efforts of the collaborative, and ultimately the results of new research stemming from it, will persuade those patients that this venture will be making a big contribution to understanding ME/CFS.

Simon McGrath has a science degree, and has watched not much happening in ME/CFS research for a long time, but now thinks things are finally kicking off. He occasionally tweets on research: follow@pSimonMcGrath

Tymes Trust - The young ME sufferers trust

Tymes Trust is the longest established national UK service for children and young people with ME and their families. It is a respected national charity whose entire professional team give their time free of charge. They work constantly with doctors, teachers and other specialists to offer a range of services. They supply expert information and are consulted by: doctors; education specialists; families; members of the press; and government departments, including The Department of Health and The Department for Education.

In 1989, two young people with ME published the first Tymes Magazine to give children with ME a voice. For the first time, there was a place for them to share experiences and needs. In 2010 The Young ME Sufferers Trust received the Queen's Award for Voluntary Service - the MBE for volunteer groups - for pursuing the educational rights of children with ME and advancing their care.

The Trust works with NHS Direct, ChildLine, ASPECT, the Nisai Virtual Academy, the Association of School and College Leaders, and has Partner ME Groups around the UK. It is also a member of the ME Alliance of charities and Forward-ME.

Support services

Children with ME are frequently unable to travel in order to meet others. The Trust's personal approach is tailored to alleviate this sense of isolation and many youngsters have made friends of their own age through us.

The Trust is committed to ensuring that children approaching us for support are respected and protected. Personal details are not passed to other organisations. The Trust's data protection policy is available on request.

Registration provides:

- full access to our support services by phone, post and email;
- welcome pack;
- membership mailings (e.g. Tymes Magazine);
- advice line service 11.00am-1.00pm and 5.00pm-7.00pm weekdays;
- professionals referral service – an expert panel can explain ME to your doctors, teachers or social workers; and
- personally signed Birthday and Christmas cards.

Each member of the 'advice line team' either has a child with ME, or has had ME themselves. You will be talking to people who understand the illness from first-hand experience. They have full information and regular updates, and telephone back-up from our expert panel. If they do not know the answer to a question, they will find someone who does.

Our 'professionals referral service' allows doctors, teachers, social workers and other professionals to consult colleagues with knowledge and experience of ME in children. If your child has ME but does not want to be registered, you may contact us to obtain our services on their behalf.

The Tymes Trustcard

The Tymes Trustcard carries your photo and is signed by your Head Teacher or college Principal. It is there to protect your needs whist in school or college. The Trustcard was endorsed on its launch by Baroness Ashton, then an Education Minister, and by the Secondary Heads Association. The second generation card for use in schools and colleges was launched in the House of Lords in 2007 by Lord Adonis, then Parliamentary Under-Secretary of State for Schools, and endorsed by the Association of School and College Leaders. It is recommended by Lord Clement-Jones CBE and the Health Minister Earl Howe.

Contact: Telephone: 0845 003 9002 between 11am-1pm and 5pm-7pm weekdays
Post: Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE

BioPQQ (pyrroloquinoline quinone)

As part of our newsletters we sometimes include information about supplements that maybe useful for ME/CFS. However, such supplements are often expensive, especially if their benefit only remains while the supplement is in use.

Problems with Mitochondria (e.g. blockages and low numbers) is a common finding and substantial theory within ME/CFS research.

PQQ increases mitochondrial biogenesis. In other words it stimulates the creation of new mitochondria. I understand that our mitochondria only live for a few weeks and so there is constantly renewal. However, PQQ increases the total number of mitochondria for as long as the supplement is taken daily. I read that once the PQQ is discontinued that the mitochondria numbers fall again.

The traditional way of increasing mitochondria numbers is daily exercise, something that is unavailable to a typical ME/CFS sufferer.

An overview of PQQ from 'Doctors Best' is included below along with a few purchasing examples.

Overview
Promotes Mitochondrial Function*

- Featuring BioPQQ™
- Authentic, Pure Pyrroloquinoline Quinone
- Ultra-Potent Antioxidant and Other Protectant Actions*
- Promotes Mitochondrial Survival and Energy Production*

Best PQQ Featuring BioPQQ supplies Pyrroloquinoline Quinone (PQQ), a polyphenol that is an exceptionally potent antioxidant and cell regulator. PQQ is found in common foods and human milk, and is a growth factor for the mitochondria that generate over 90 percent of our life energy. PQQ promotes mitochondrial survival, proliferation, and function.

*These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.

Purchasing examples

- Doctors Best PQQ - 30 x 20mg Vegicaps Price: £38.99 From: www.bodykind.com

  Link (for those who receive the newsletter by email):

  http://www.bodykind.com/product/4782_129-Best-PQQ-Mitochondrial-Function-30-x-20mg-Vegicaps.aspx?Referer=Google_doctors%20pqq&gclid=COXj7qGo2bcCFVMbtAodeFQAjw

- Life Extension PQQ Caps with BioPQQ, 30 x 20mg Vegicaps Price: £25.93
  From: www.amazon .co.uk

  Shipped from America (shipping cost included in price), so takes a number of weeks to arrive.

Gut bacteria – the cause of M.E. ?

Source: www.telegraph.co.uk/health/5407749/ME-Proof-that-it-isnt-all-in-the-mind.html

Anna's deterioration was rapid and unrelenting. One moment the pretty, young Scandinavian woman was at the peak of youthful vitality, newly married and excited about the future. The next, that future was much diminished, her life limited to the environs of her bedroom, and dictated to by the illness that had overwhelmed her.

It had started with persistent fatigue, muscle pain, and a growing sensitivity to light after a honeymoon trip to Mexico in the summer of 2006. By December, she was in a wheelchair. Three months later she was bedridden, her face pale, her features shrunken, barely able to move or talk, and being fed through a naso-gastric tube.

Anna – not her real name as her identity is being protected at the request of her family – was the subject of a short film shown at a conference in London last week. Her case, according to Professor Kenny De Meirleir of the Vrije Universiteit Brussel, Belgium, illustrates the worst ravages of myalgic encephalomyelitis/encephalopathy or ME, also known as chronic fatigue syndrome or post viral fatigue syndrome.

Once it was derided as "yuppie flu" because, following its emergence in the early Eighties, its "typical" victim was, supposedly, a high-achieving young professional. ME was also assumed by many doctors, and much of the public, to be psychosomatic in origin – if it existed at all.
In more enlightened times, ME is now accepted by the World Health Organisation, and Britain's medical royal colleges, as a complex, chronic disease of varying severity characterised by a complex set of symptoms. (In addition to extreme fatigue, and general malaise, there are musco-skeletal symptoms, especially muscle pain, brain and central nervous symptoms, evidence of immune system dysfunction, mood swings, depression etc.) According to the ME Association, there are 250,000 sufferers in Britain.

The debate about the cause of ME continues to flourish at conferences, in journals and on websites: are the symptoms a physical manifestation of a problem in the brain such as a chemical imbalance; is sustained stress or exertion to blame; or is ME the result of abnormal physiological functioning, with an organic cause, such as a viral or bacterial infection, or exposure to a toxic agent?

The answer is crucial because it determines the direction of research funding which has, according to Prof De Meirleir, for too long been skewed in favour of a psychiatric approach. He hopes to change that. After more than 20 years of investigation, and having assessed and treated thousands of patients in Europe and America, Prof De Meirleir, who is an internist at the Himmunitas Foundation in Brussels (a non-profit organisation specialising in chronic immune disorders), believes he has identified a mechanism to explain the development of ME that opens up new treatment options.

In addition, he and his fellow Belgian, Dr Chris Roelant, Chief Operating Officer of the diagnostics company Protea biopharma, have developed a self-diagnosing urine test for ME. If they are correct – and that must be determined by scrutiny of their research and use of the test by other scientists and doctors – then it marks an encouraging breakthrough. The symptoms of ME are wide-ranging and occur in a number of other conditions, so a diagnosis of ME is currently reached only after eliminating other causes. "This test will tell patients that it is not a problem between their ears, but a real physiological problem," insists Dr Roelant.Prof De Meirleir and Dr Roelant have, somewhat controversially, opted to go public with their findings before publication in a peer-reviewed journal. They say this is because of the implications of their research, especially for severely debilitated ME patients. At the Invest in ME conference in London last Friday they also raised the possibility of "transmissability" of the illness in this group of patients – another controversial claim.

Prof De Meirleir has never believed that ME is an "illness of the mind". Exercise physiology was his initial area of expertise and it was in this capacity that he was asked by a psychiatrist to assess some of his patients who were suffering from a mystery illness characterised by extreme fatigue.

"One of them was a banker who started work at 9am and had to finish at 11am because he was so exhausted," says Prof De Meirleir. "He did not appear to be suffering from any psychiatric disorder."

The case ignited the young doctor's interest. During a six-month sabbatical at the University of Pennsylvania in 1990, he heard about the "Lake Tahoe epidemic". In 1984, hundreds of people living in a small town on Lake Tahoe in California succumbed to a flu-like illness. The symptoms, including fatigue, neurological and immunological symptoms, persisted in just under 10 per cent of the population (about 300). This was followed by numerous reports of outbreaks of a similar illness around the world, and persuaded Prof De Meirleir of the likelihood of a causative agent being involved in ME, a fact that has heavily influenced his research interests. Since the early 1990s, he has built up a large clinical practice in Brussels where he sees around 2,000 new patients a year. Antibiotics are a cornerstone of his therapeutic approach, as dictated by his research.

In recent years, and in collaboration with a microbiologist, Dr Henry Butt, and his team at the University of Melbourne, Prof De Meirleir has focused on bacteria in the gastro-intestinal tract. "This is an obvious place to start since 80 per cent of immune system cells are located here," he says. A healthy, functioning gut is colonised by "good" bacteria that aid digestion and contribute to our wellbeing. Many ME patients suffer from multiple intestinal symptoms, and Prof De Meirleir believes that an overgrowth of "bad" bacteria, including enterococci, streptococci and prevotella, is to blame. These bacteria are normally present in very small quantities in a healthy gut, but can initiate a sequence of events leading to the multifarious symptoms of ME if they proliferate. (This research will be published in the journal In Vivo, in July).

These "bad" bacteria produce hydrogen sulphide (H2S)– a gas naturally occurring in the body, where it has several functions – in minute quantities. However, in larger quantities, it is a poisonous gas that suppresses the immune system, and damages the nervous system, according to Prof De Meirleir. (Hydrogen sulphide is produced by some animals in preparation for hibernation because it "shuts down" the body which, in effect, is what occurs in ME.) In addition, Prof De Meirleir described how he believes the gas reacts with metals, including mercury, introduced in minute amounts as contaminants in food. The form of mercury produced after reacting with hydrogen sulphide also disrupts the normal production of energy (known as the Krebs Cycle) by individual cells, and this, he says, would explain the energy shortfall experienced by ME patients.

Normal cellular functioning is inhibited and, over time, this generates damaging free radicals, highly reactive molecules that distort the structure of key proteins, such as enzymes and hormones, necessary for chemical reactions. This results in what Prof De Meirleir calls "aberrant" proteins (or prions), which lead to further symptoms as the body is increasingly compromised, and which he says may play a role in the transmissibility of ME.

The urine test, developed by Prof De Meirleir and Dr Roelant in their privately funded research, detects the presence of hydrogen sulphite metabolites, which they say confirm the presence of abnormal quantities of hydrogen sulphide-producing bacteria. The intensity of the colour change in the urine indicates the severity of the disease progression.

Not every ME patient progresses to its most severe form, says Prof De Meirleir, but the varying symptoms can all be explained by this proposed mechanism for the disease. In the worst cases of ME, he says it can be shown that there is an almost complete eradication of "good" bacteria (such as E. coli), the presence of a high number of "bad" bacteria in stools, metal deposits in tissues, and the presence of aberrant proteins in saliva. "What we have shown is that these patients have an organic disease involving one of the most toxic substances [H2S] that exist," he says.

So what causes the proliferation of harmful bacteria in the first place? There are, he says, many potential triggers ranging from food- borne bacterial (eg salmonella) infections, viruses, and toxins, or mental stress. He says many ME sufferers have a history of gut disorders including gluten and lactose intolerance, which may predispose them to colonisation by enterococci and streptococci.

Anna, the 28-year-old Scandinavian patient, is typical in this respect, he claims; she had gut problems in the past, including possible food poisoning while in Mexico. Her treatment focuses on short courses of antibiotics to decrease the numbers of bad bacteria, treatment with probiotic supplements to help restore the good bacteria, plus vitamin and mineral supplements. "She is improving," says Prof De Meirleir.

ME support groups and the medical profession are now considering Prof De Meirleir's work. However, Sir Peter Spencer, chief executive of Action for ME, welcomed the findings, albeit with a caveat: "It is always heartening to see new developments that might bring hope to the 250,000 people in the UK affected by this horrible illness.

"We look forward to seeing Professor Meirleir's findings published in a peer-reviewed journal so that we can develop a better understanding of this research."

Prof De Meirleir says that helping patients like Anna, of whom he has known many, is what has brought him to this point. "This has preoccupied me for more than 20 years. I told [the psychiatrists] we would find a cause, and I believe we have." There are many ME patients and their families who must hope that he is right.

For more information on the ME urine test see www.proteabiopharma.com

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Daily cytokine fluctuations, driven by leptin, are associated with fatigue severity in CFS

Full article: www.translational-medicine.com/content/11/1/93

Chronic fatigue syndrome (CFS) is a debilitating disorder characterized by at least six months of persistent fatigue that is not alleviated by rest. Individuals with CFS often report additional symptoms such as muscle pain, joint pain, headaches, poor sleep, inability to concentrate, sore throat, swollen lymph nodes, and post-exertion malaise. The condition affects an estimated 42 out of every 10,000 – equating to approximately one million – individuals in the United States. In addition to the impact on quality of life, it presents substantial costs to the economy in both direct medical expenditures and lost work productivity. The majority of diagnosed individuals are adult women.

The development of effective treatments for CFS has been hindered by the lack of a clearly identified pathophysiological mechanism for the disorder. There are no objective blood tests to confirm a diagnosis, and no well-accepted targets for intervention. Several studies, however, have demonstrated abnormal inflammatory processes in CFS. Cross-sectional analyses (CFS versus healthy control) have identified elevated levels of pro-inflammatory cytokines such as TNF-alpha, IL-1alpha, IL-1beta, and IL-6 [5,6]. Results, however, are inconsistent across studies [7], and no potential biomarkers have been consistently supported by research to advance diagnosis or treatment.

One challenge of research to date is that individuals with CFS exhibit significant day-to-day variability in their fatigue severity. This within-subject variability may reduce the sensitivity of cross-sectional studies to consistently identify immune abnormalities in these individuals [8]. We have therefore tested a within-person, daily immune monitoring approach for identifying CFS biomarkers. By measuring immune markers over many consecutive days, we sought to identify serum analytes that “track” increases and decreases in fatigue severity. This intensive longitudinal approach may reveal novel biomarkers overlooked by traditional cross-sectional immune studies and unveil novel mechanisms in CFS pathogenesis.

The technique may be particularly useful in cases where daily symptom variability introduces statistical noise in cross-sectional data, or when immune factors exist in normal concentrations, but still drive pathological processes because of sensitized targets. Our goal with this approach is to identify biomarkers that facilitate diagnosis and may be targets of future therapies.

We previously piloted the daily immune monitoring approach in three women with fibromyalgia (FM) and co-morbid CFS. The participants were monitored for 25 consecutive days, and their daily serum samples analyzed for concentrations of 51 different cytokines. Out of the 51 analytes, only leptin was significantly correlated with day-to-day self-reported fatigue severity in all three women. Leptin is an analyte of interest because, in addition to being an appetite-regulatory hormone, the adipokine is an inflammatory agent that has been linked to pathological inflammatory fatigue. Leptin provokes the release of pro-inflammatory cytokines from many cell types, including centrally acting microglia, and is a mediator of cytokine-induced sickness behaviour.

Given the results of our preliminary data, we designed a study comparing ten women with CFS to ten healthy, age-, sex- and BMI-matched controls. Participants underwent 25 consecutive days of blood draws, and completed reports of fatigue severity twice a day. We hypothesized that leptin would be associated with daily fatigue severity in the participants with CFS but not in healthy controls. As a secondary, exploratory aim, we also tested the ability of 50 other immune factors to predict fatigue variability in both groups. To our knowledge, this is the first study of leptin and its role in CFS.

Results
Self-reported fatigue severity was significantly correlated with leptin levels in six of the participants with CFS and one healthy control, supporting our primary hypothesis. The machine learning algorithm distinguished high from low fatigue days in the CFS group with 78.3% accuracy.

Conclusions
Our results support the role of cytokines in the pathophysiology of CFS.

DVD of the 2013 Invest in ME conference

Contents

- Dr Ian Gibson - Welcome to the Conference
- Dr Daniel Peterson - The Mainstreaming of ME Research
- Dr Andreas Kogelnik - Strategies for ME Research and Collaboration
- Dr Rakib Rayhan - The Role of the Brain and ME
- Professor Greg Towers - Retroviruses and ME
- Professor Mady Hornig - Pathogen Discovery in ME
- Dr Clare Gerada - Govt NHS Reforms: Implications for long term chronic conditions such as ME – for GPs and Patients
- Professor Sonya Marshall-Gradisnik - Current Knowledge of Immunological Biomarkers
- Dr Amolak Bansal - Clinical Immunology and Research on B-cell Abnormalities in ME Patients
- Professor Carmen Scheibenbogen - Immunological Basis of ME
- Professor Olav Mella - B-cell Depletion Therapy Using Rituximab in ME/CFS - Part I
- Dr Øystein Fluge - B-cell Depletion Therapy Using Rituximab in ME/CFS - Part II
- Dr Ian Gibson – Questions

Ordering
The DVD can be ordered online at the following website: http://investinme.org

Or, by post by sending a cheque for £14 to –
Invest in ME, PO BOX 56, Eastleigh, SO50 0GQ, Hampshire, UK

Please supply your name and address (and email address if possible) and mark that you require the UK (PAL) version.