Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

September 2013

Change of newsletter title

Until now, our newsletters have been titled by the name of the season that they reported about. So, our Summer newsletter contained the latest ME news from the Summer and was released before the last month of the Summer. However, this system meant that our newsletters felt like they were arriving almost out of season and a “Winter 2012” newsletter arriving in February 2013 could seem miss-placed.

We will still produce four newsletters a year at roughly the same time as before but simply giving them the title of the month that they are released.

Future dates

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

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

25th September 2013 (Wednesday) 11am The Seahorse
The Street, Shalford, Guildford, GU4 8BU

15th October 2013 (Tuesday) 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.

6th November 2013 (Wednesday) 12 noon 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.

Future dates are continued overleaf...

26th November 2013 (Tuesday) 7.30pm Bridge Barn
The Bridge Barn, Bridge Barn Lane, Woking, Surrey, GU21 1NL

We have recently become aware of a number of new ME sufferers in Woking who are keen to meet. As such, we are trying Woking again as a venue.

Directions: From Guildford:
1. Head northwest on North St/A320 toward Chertsey St
2. Turn right onto Chertsey St/A320. Continue to follow A320. Go through 7 roundabouts
3. At the roundabout, take the 1st exit onto Wych Hill Ln
4. At the roundabout, take the 2nd exit onto Trigg's Ln
5. At the roundabout, take the 3rd exit onto Goldsworth Rd
6. At the roundabout, take the 1st exit onto Bridge Barn Ln

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Warning:
Booking required

Christmas Dinner

9th December (Monday) 7.30pm The Seahorse
The Street, Shalford, Guildford, GU4 8BU

If you would like to come along to the Christmas Dinner please phone Maggie, our Chairperson, on Tel. We automatically reserve 10 seats for the Christmas Dinner and places are taken on a first come, first served basis. If we receive more than 10 requests we will attempt to book additional seating. Please phone as soon as you believe that you can come.

An overview of Dr Myhill's approach

We are all familiar with:

- how numerous and intense the symptoms of ME are or can be;
- the limited ability of the mainstream medical profession to help; and
- the Kafkaesque (menacing surreal distortion) experience of a significant proportion of the medical profession and society deeming ME to be 'all in the mind', despite:
    - overwhelming biological research to the contrary (5000+ research papers),
    - the World Health Organisation's categorising of ME as neurological since 1969 and;
    - the International Consensus Criteria of 12 countries defining ME as:

> *"An acquired neurological disease with complex global dysfunctions. Pathological dysregulation of the nervous, immune and endocrine systems, with impaired cellular energy metabolism and ion transport are prominent features."*

In fact, the UK Department for Work and Pensions still categorise ME and CFS as a mental disorder.

Luckily there are a few doctors in the world doing everything they can to support ME sufferers, despite the uninformed and constrained mainstream. One such doctor in the UK is Dr Myhill.

Dr Myhill is based in Wales and could be described as a private fatigue specialist and Champion of ME support. She provides a website and book (free to download) that provide information on biology, tests, diet, supplements, medication and treatments. Her aim is to empower individuals to help themselves. Subject to cost, her office help you to access certain medical tests and Dr Myhill provides an interpretation of the results and recommends associated actions.

Dr Myhill's website is: www.drmyhill.co.uk

Dr Myhill's free book/guide to treating ME can be downloaded from:
www.drmyhill.co.uk/drmyhill/images/7/76/Cfs_book_27.pdf

Below, I've included: further information about Dr Myhill; and a brief overview of her treatment approach.

Dr Myhill

"I have worked in NHS and private practice since qualifying from the Middlesex Hospital Medical School in 1981 (medicine with Honours). For 17 years I was the Hon Secretary of the British Society for Ecological Medicine (renamed from the British Society for Allergy, Environmental and Nutritional Medicine), a medical society interested in looking at causes of disease and treating through diet, vitamins and minerals and through avoiding toxic stress. I help run and lecture at the Society's training courses. I lecture regularly on organophosphate poisoning, the problems of silicone, CFS and so on. I have had many appearances on TV and radio. I am a founder member of OPUS (organophosphate users support group) – a charity to help sufferers of pesticide poisoning.

I am a co-author of a scientific paper "Chronic fatigue syndrome and mitochondrial dysfunction" which has been published (Jan 2009) in the International Journal of Clinical and Experimental Medicine – see http://www.ijcem.com/files/IJCEM812001.pdf This paper supports the fact that the mitochondrial function test is very useful because it gives an objective measure of fatigue which cannot be argued with."

Dr Myhill

Dr Myhill's approach

"My aim is to give all CFS sufferers and their therapists the knowledge and the access to information and tests to get themselves on the road to recovery.

I estimate that in my working life I have seen and treated thousands of patients with CFS. I now know that there is a route to get well which entails a whole package of treatment. That package of treatment has to be done in the right order – it is a little bit like building a house – there is no point putting the upstairs windows in until the foundations and walls are in place.

Many patients come to me having tried thyroid or B12 injections, for example, but unless the diet, sleep, pacing and micronutrients are in place and correct, they may not see benefit. I ask all my patients to tread this hard path because I know of no other way to get better. This requires a complete change in lifestyle and changes are hard to make, especially when the poor patient lacks the physical, mental and emotional energy to make these changes at all!

Each patient has to become his own doctor, detective and psychotherapist to work out the best strategies for recovery. I can point patients in the right direction, provide the tests, information and therapies to get sufferers better, but there is only one person who can actually walk that path.

The basic package of treatment and approach to treatment is the same for everybody, but each person discovers a vital key or keys which really give them a quantum leap in improvement and may even be unique to them. For some people who are poisoned it is the detox regime that makes them better. For others, removing mercury amalgam opens the floodgates to recovery; thyroid hormones for many are an important factor. But there is no point putting the esoterics in place until the basics are done.

Recovery is never a smooth ride because life has a habit of getting in the way and throwing in extra stresses that you can do without. Whenever a hiccup occurs, always go back to the basics. People recover from CFS, firstly by getting their regime as tight as possible (with respect to diet, supplements, pacing, sleep and detox), then they start to feel better and only then should they start to increase their levels of activity. BUT if they get delayed fatigue, then activity must be reduced. Most people end up with a juggling act between how strict their regime is, how well they feel and how much they can do.

The regime is for life – but once in place it substantially reduces risk of heart disease, cancer and degenerative conditions.

I treat CFS by working out the underlying nutritional, biochemical, immunological, toxic, hormonal, and lifestyle mechanisms that cause the symptoms and signs. Compare the body with a car.

If the body is a car…to get it to go you need:

Engine	Mitochondria
Fuel	Diet
Oxygen	Lungs
Accelerator pedal	Thyroid
Gear box	Adrenal
Service and repair	Sleep
Cleaning and Oil	Antioxidants
Catalytic converter	Detoxification
A driver	The brain

In practice I treat CFS patients in the following order, starting with the things that everyone should do all the time then add on the extras if they do not recover with this simple package of treatment.

Rest
80% rule, pacing, mental and physical rest. Get organised. Accept help. Arrange for deliveries to house. Delegate work. Prioritise. List the 10 most important things in your life, and then ignore the last five. You can't do everything. Look after your mitochondria!

Nutritional supplements
It takes at least 6 months for body stores to replete. Supplements are for life.

Sleep
Quality sleep is essential to life. Don't be afraid to use tablets to restore the normal day/night diurnal rhythm.

Stoneage diet
Humans evolved over thousands of years eating a Stoneage diet. We should all move towards eating such a diet made up of foods of low glycaemic index which avoids the common allergens (grains, dairy, yeast, artificial food additives). I now also recommend routine use of DIY Probiotics such as Kefir.

Treat the mitochondrial metabolic dyslexia
Which may include some of the following:

a. Correcting levels of:

D-ribose
Antioxidants (Co-enzyme Q10, Acetyl-L-carnitine, B12, glutathione)
Magnesium (injections)
Niacinamide

b. Detoxing
c. Tackling hormonal imbalances
d. Tackling hyperventilation

Detox
Reduce your chemical load by:

Avoiding alcohol, care with caffeine, many prescription drugs (especially statins, diuretics, beta blockers, antidepressants, Pill and HRT) make CFS much worse. We now know why – they inhibit mitochondria. Don't take the Pill or HRT– they worsen CFS in the long term and certainly predispose to getting CFS because they suppress the immune system and induce nutritional deficiencies. Many IUCDs (coils) also contain hormones. Depot injections are the worst! Fertility treatments are often disastrous for CFS.

Do a good chemical clean-up of your environment – throw out all the smellies in your house, keep the house well ventilated, avoid sprays, polishes, aerosols, new paints, new carpets, gas cookers and heaters etc.

Consider detoxing with a "sweating regime" such as FIR. These gets rid of all toxins – heavy metals, pesticides and volatile organic compounds but it is important to rehydrate with beneficial minerals since these too are lost in sweat. Actually it is not essential to sweat for FIR to be effective – fat soluble toxins are mobilised onto the lipid layer of the skin and then can be washed off. There are many ways which one can detox.

Avoid infections whenever possible
Do not permit visitors who have a cold!

Improve nutritional status – especially vitamins D and C.

Check for Hypochlorhydria.

At the first sign of a cough, cold or sore throat use high dose micronutrient such as vitamin A (not if pregnant), vitamin C, zinc, selenium and propolis. Don't be afraid to take high dose vitamin C to bowel tolerance – if you take too much the worst that can happen is diarrhoea. I need 10-20 grams in 2 hours to stop a cold. You may need more. With infections your need and your tolerance of vitamin C increases markedly.

Also use the neutral form of vitamin C (e.g. magnesium ascorbate) to dissolve in the mouth to kill microbes in there.

Consider heat and sweating to get rid of viruses – they are quite temperature sensitive!

Allow time for recovery
First, get the regime tight, then feel well doing very little. Then gradually increase activity so long as you continue to feel well.

(by which I mean no loss of stamina or delayed fatigue). Feeling ill results from useless inflammation in the body causing a high cell-free DNA, which has the potential to switch on allergies and/or autoimmunity. Feeling ill can make you more ill, it is a disease amplifying process."

Dr Myhill

Meditation for ME/CFS

In this Meditation for ME/CFS section I've included:

- an overview of meditation for ME/CFS;
- links to research information about the benefits of meditation for ME/CFS;
- information about local free meditation classes that a few of our group use; and
- information about TM meditation that is used by our Chairperson.

An overview of meditation for ME/CFS
Source: www.answerstochronicfatigue.co.uk/meditation-for-me-and-cfs.htm

Research has shown that significant benefits are evident from regular meditation. It can help people who suffer from chronic pain and is also one of the most ancient, proven methods for relieving stress, a common factor that prevents wellbeing. Meditation has also been shown to in many cases improve sleep patterns, increase energy and enhance the body's ability to heal itself.

Physically, meditation can lower the level of cortisol (stress hormone) in the body. Mentally, it strengthens your minds' ability to disengage from worries, pain, stress, and illness, allowing you to cultivate a focus on something completely unrelated to your life, your pain, or your illness. Other specific benefits of Meditation for ME and CFS can include:

Mental and emotional benefits of meditation:

- More even moods, fewer mood swings
- Reduced anxiety
- Increased energy and vitality
- Improved memory and cognitive function
- A sense of peace and calm
- Reduced Stress
- Reduced depression

Physical benefits of meditation:

- Reduced heart rate
- Lowered blood pressure
- More balanced nervous system
- Better Sleep
- May help balance the immune system to help the body resist disease and heal
- Less physical stress and a more balanced autonomic nervous system (which is what governs the stress response in the body)

Meditation is an ancient practice used by many cultures as a way of experiencing a deeper spiritual connection or a freeing from the struggles of the everyday material world.

There are vast number of different meditation practices; following the breath, repeating a sound or a mantra, visualisation and mindfulness meditation.

Meditation creates space for a person to take a break from the endless chattering of the mind and the worries and stress of everyday life. It can develop a feeling of relaxation and peace, whilst producing mental alertness and clarity. Meditation trains you to let feelings or thoughts that arise pass without reaction. The wandering attention is gently brought back to the meditation.

Studies show that it does not seem to matter what meditation techniques are used. Regular practice would seem to be the most important criterion.

A study conducted in 1993, tested the effects of daily meditation on 77 Fibromyalgia patients. It found that 51% of participants reported moderate to significant improvement in their symptoms. In 1998, researchers studied the effects of meditation on Fibromyalgia. They deduced that meditative practices lessened the aches, muscle pain, sleeplessness and depression experienced by people with this condition.

Another 1998 study revealed that people with CFS who used mind/body medicine practices such as meditation tripled their chances of improvement over a one year period, compared people with CFS who did not take engage in these practices. A link to a PDF of the study:

fhttp://journals.sfu.ca/seemj/index.php/seemj/article/view/256/219

Meditation is not a cure for ME, FM or CFS; it is an ancient tool that can help relieve symptoms and increase your ability to take control of your wellbeing.

Links to further research information for the benefits of meditation for ME/CFS
Reduces neurogenic inflammation: www.ncbi.nlm.nih.gov/pubmed/23092711

Reduces chronic inflammation: www.sciencedaily.com/releases/2013/01/130116163536.htm

Eases the impact of emotional pain: www.sciencedaily.com/releases/2010/06/100602091315.htm

Information about local free meditation classes that a few of our group use
Below are a few links and information to local free meditation classes.

New Buddha Way
www.newbuddhaway.org

If you would like to attend our sessions in Guildford and/or Woking you are advised to first take part in our free Beginners' and Newcomers' Class, which we put on about once a month.. This applies equally to those who have never meditated before and those who have done so for years. We have found over the years that this 'gateway' makes for a beneficial experience both for regular participants and the newcomers.

The class is free of charge, and there is free parking nearby. Please let us know if you are coming to the class by sending an email to info@newbuddhaway.org and we shall send you an invitation and details. For directions and maps see the Woking and Guildford pages on our website.

The next scheduled Beginners' and Newcomers' Class will be on Sunday 15th September 2013 from 11.30 to 13.30 at The Quiet Centre, University of Surrey, Guildford.

Email us at info@newbuddhaway.org to book a place, receive the date, details and directions.

- No prior knowledge is required and there is no need to bring anything.
- Instruction will be given in meditation practice and posture with short exercises.
- The Buddha's teachings will be introduced.
- We use no convoluted terms or jargon, only plain English language.
- The session will allow for open discussion and questions.
- There will be a break for drinks and biscuits.
- You are not required to sit on a cushion unless you wish to.
- The class is suitable for all age groups.
- Please do not arrive until 11 am earliest, because the previous meditation session finishes at that time.
- The class is completely free, but to help us cover costs donations are always appreciated.

Café Mila
http://cafemila.co.uk/index.php
1 Angel Court, Godalming GU7 1DT
Tel: 01483 808569

Imagine a light and airy space suspended above a quiet courtyard. Secluded by night; energised by day by the buzz of a lively café. Welcome to the studio at Cafe Mila in Godalming.

First-rate teachers work here, offering a range of styles and approaches. Which means that you’re sure to find a class that’s right for you, no matter what your age or ability.

We offer beginners’ courses, Kids’ yoga, opportunities for self-practice, advanced sessions, pregnancy yoga, workshops, and regular meditation evenings. Something, in other words, for everyone.

Regular meditation sessions are held on Sunday evenings. These usually start at 6pm, but times may vary depending on the season and/or workshops

Sahaja Yoga meditation meetings (weekly and free)
www.meetup.com/Free-Meditation-Yoga-Surrey

We'd like to welcome you to our meetings which take place on Wednesdays at 6.30pm at the Weybridge Committee Room (1st floor), Church Street, Weybridge, KT13 3DX

We are all volunteers of a Charity organisation and have many years of experience in offering free Sahaja Yoga Meditation classes.

Information about Transcendental Meditation (TM) that is used by our Chairperson – Maggie Lilley

“I have been practising Maharishi Mahesh Yogi’s Transcendental Meditation for the past 47 years. Maharishi brought TM to England in the mid 1950’s and the practice is now world-wide.

With no straining or concentration, with eyes closed and repeating a mantra which is a sound given by the TM Teacher 20 minutes twice a day keeps me calm, peaceful, relaxed, invigorated and happy! It was immensely helpful during bouts of M.E.

I would urge anyone to avail themselves of this most productive and life affirming practice. Fees are on a sliding scale according to earnings, and this initial payment covers you for life.

The course fee covers the full six-month programme of learning the technique and becoming thoroughly self-sufficient in the practice, with as much personal attention as required. Payment may be made by a variety of methods and instalments are also possible. The fee is on a sliding scale and associated information is included on the website.

As an example the concessions price is: £290
(students aged 18 and over in full-time education, registered unemployed, state pensioners, and cases of special need)

My dear friends Pat and Alaric Law are now teaching TM in Guildford and would be happy to hear from you and answer any queries you may have. The TM website is given below”.

http://uk.tm.org/web/guildford

Maggie Lilley

Stephen Holgate – A man who likes a challenge

Not many scientists choose to work with ME/CFS. Even fewer when, like Stephen Holgate, they already have impressive careers (he's made several key discoveries about asthma for example). But Holgate positively sought out ME/CFS research and its politics.

He told the former Chief Executive of the Medical Research Council (MRC) that ME/CFS was a problem that needed sorting out – and was promptly asked to attempt just that. He began in late 2009 with a workshop and the MRC Expert group on ME/CFS, which ultimately led to MRC grants of £1.6 million ($2.3 million) for biomedical research in 2012. It was followed by the launch of the UK CFS/ME Research Collaborative (CMRC) earlier this year, endorsed by the MRC and two other major research institutions.

So Stephen Holgate gets things done, but why did he choose to get involved? In an interview he revealed that what he most loved about being a scientist was new challenges, particularly helping others who deal with "complex issues around complicated diseases" – a nice summary of ME/CFS, which he gave as an example.

Asked what he would like to be remembered for as a scientist he replied: "That I was prepared to listen and take on difficult challenges and continue even if prevailing opinion was against me!"

This could be just what the field needs. Stephen Holgate is the MRC Clinical Professor of Immunopharmacology and has been a visiting professor at both Harvard and Yale universities in the US.

A dozen different diseases? Stephen Holgate calls for radical change in ME/CFS research

Source: http://phoenixrising.me/archives/18222
By Simon McGrath
August 15, 2013

Professor Stephen Holgate says ME/CFS is a spectrum of disorders that need to be understood through new approaches, and patients must be partners in research. Simon McGrath reports.

ME/CFS probably isn't one disease, or even a few different ones – but could be as many as fifteen. So said Professor Stephen Holgate, Chair of the UK Research Collaborative (CMRC), when he addressed the Forward ME Group in the House of Lords on 2nd July. He also argued that a radical New Science was needed to tackle ME/CFS and said patients must be partners in research. Not bad going for one talk.

More than a dozen different diseases?

Most researchers believe ME/CFS is more than one disease, and quite a few believe even ME is more than one, but I was surprised when Stephen Holgate said that ME/CFS could have twelve to fifteen different 'causal pathways'. That's an awful lot of different illnesses mistakenly lumped together in one pot. I asked Stephen about the number and he said that at this stage nobody knows for sure, but it's highly likely to be fifteen or even more disease process, given it's such a heterogeneous condition. There are, he mentioned, fourteen different causal pathways in Breast Cancer, seemingly a far more uniform illness. However, he added that some of the ME/CFS causal pathways will probably be interlinked, so it could come down to five or six underlying disease mechanisms. That would still be half-a-dozen different diseases – and it could yet be more. Stephen refers to ME/CFS as 'a spectrum of disorders' and has said that looking for the cause is a lost cause (Nature Reviews: Neuroscience 2011).

New Science needed

With such complexity, it’s perhaps not surprising that little progress has been made to date. Professor Holgate said some researchers new to the field had been shocked by the poor quality of much ME/CFS research, and even commented that some had ‘made a career’ out of ME/CFS theories that could be shaky.

Also, while medicine has made great progress in many areas, it has been struggling to tackle the remaining problems, particularly chronic illnesses. A fundamental issue, he said, is “the breakdown of the linear relationship between cause and effect”. That was a bit over my head, so I asked him to elaborate: he’s always been amazed by the ability of our bodies to restore themselves in response to adversity, such as an infection – either compensating in part or restoring normal function. He believes that the complex networks responsible for this ability of the body to restore itself have gone awry in ME/CFS, and perhaps other chronic illnesses too. He says the only way to tackle such a complex problem is, ultimately, to track down and understand the individual causal molecular pathways: if you know the pathway you know the way to deal with the disease, and that was the way to get the drugs industry involved. Identifying the pathways is a big challenge, but Stephen Holgate believes that now is a fantastic time to study ME/CFS as new techniques emerge that are up to the job.

Mega-study planned: 5,000 patients

To have any hope of identifying many different diseases (or causative pathways) within the umbrella definition, a lot of patients are needed; and there are early plans for a study involving a 5,000-strong cohort of patients. The idea is to explore everything: phenotypes, genotypes, gene expression, cells, cytokines, metabolites and more. Some of these individual features have been researched before, but not all together: and never on such a scale. High quality scientists would then have to be involved to look at applying the new technologies to the data generated from patients. But there has to be a multi-disciplinary approach, and nurses, for example, would be just as important as mathematicians in this operation.

New computer technology would be used to probe the mass of data, with the aim of finding distinct groups of patients who ‘cluster’ together with similar features, which should make it easier to home in on different causal molecular pathways in different types of patients. It is identifying causal pathways that will lead to a much deeper understanding of ME/CFS and, hopefully, provide targets for drug therapy too.

Stephen Holgate’s vision for ME/CFS research requires a radical change. The majority of research funded in the UK to date assumes that whatever triggers ME/CFS, it is perpetuated by patients’ flawed beliefs and behaviours. The new approach focuses instead on differences between patients, to see what this might reveal about different underlying causal mechanisms. Though of course, as yet, nothing is proven. Also, if he is right, and there are up to fifteen different causal processes involved, it might explain why biological findings have been inconsistent across the small-scale studies we have seen to date.

Patients as partners in research

Stephen Holgate acknowledged that over the years there had been a breakdown of trust between patients, healthcare providers and researchers. He wants to change that, pointing out that in most areas of medicine the patient voice was now valued and recognised. The ME Association’s Dr Charles Shepherd said the new CMRC Executive wants patients to attend meetings so that they could meet researchers. Holgate added it was also so patients can help set the research agenda – wow!

Patients, charities and the public must come to the CMRC’s Annual CFS/ME Scientific Conference, which starts next year (details yet to be announced). He would like to set a half-day aside for patient involvement, but is discussing with charities how best to do this.

With plans to engage with patients in setting the research agenda, and a new approach to research, we could well be at the start of a new era in the UK for the understanding of ME/CFS.

Note: unfortunately I wasn’t at Forward ME Group meeting, and wrote this from the extensive meeting minutes, with some additional information from Stephen Holgate himself. Any errors are my own.

USF- led study suggests some CFS patients may benefit from anti-herpesvirus drug treatment

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=18239

Tampa, FL (July 25, 2013) – Many experts believe that chronic fatigue syndrome (CFS) has several root causes including some viruses. Now, lead scientists Shara Pantry, Maria Medveczky and Peter Medveczky of the University of South Florida's Morsani College of Medicine, along with the help of several collaborating scientists and clinicians, have published an article in the Journal of Medical Virology suggesting that a common virus, Human Herpesvirus 6 (HHV-6), is the possible cause of some CFS cases.

Over 95 percent of the population is infected with HHV-6 by age 3, but in those with normal immune systems the virus remains inactive. HHV-6 causes fever and rash (or roseola) in infants during early childhood, and is spread by saliva. In immunocompromised patients, it can reactivate to cause neurological dysfunction, encephalitis, pneumonia and organ failure.
"The good news reported in our study is that antiviral drugs improve the severe neurological symptoms, including chronic pain and long-term fatigue, suffered by a certain group of patients with CFS," said Medveczky, who is a professor of molecular medicine at USF Health and the study's principal investigator. "An estimated 15,000 to 20,000 patients with this CFS-like disease in the United States alone may ultimately benefit from the application of this research including antiviral drug therapy."

The link between HHV-6 infection and CFS is quite complex. After the first encounter, or "primary infection," all nine known human herpesviruses become silent, or "latent," but may reactivate and cause diseases upon immunosuppression or during aging. A previous study from the Medveczky laboratory showed that HHV-6 is unique among human herpesviruses; during latency, its DNA integrates into the structures at the end of chromosomes known as telomeres. Furthermore, this integrated HHV-6 genome can be inherited from parent to child, a condition commonly referred to as "chromosomally integrated HHV-6," or CIHHV-6. By contrast, the "latent" genome of all other human herpesviruses converts to a circular form in the nucleus of the cell, not integrated into the chromosomes, and not inheritable by future generations.
Most studies suggest that around 0.8 percent of the U.S. and U.K. population is CIHHV6 positive, thus carrying a copy of HHV-6 in each cell. While most CIHHV-6 individuals appear healthy, they may be less able to defend themselves against other strains of HHV-6 that they might encounter. Medveczky reports that some of these individuals suffer from a CFS-like illness. In a cohort of CFS patients with serious neurological symptoms, the researchers found that the prevalence of CIHHV-6 was over 2 percent, or more than twice the level found in the general public. In light of this finding, the authors of the study suggest naming this sub-category of CFS "Inherited Human Herpesvirus 6 Syndrome," or IHS.

Medveczky's team discovered that untreated CIHHV-6 patients with CFS showed signs that the HHV-6 virus was actively replicating: determined by the presence of HHV-6 messenger RNA (mRNA), a substance produced only when the virus is active. The team followed these patients during treatment, and discovered that the HHV-6 mRNA disappeared by the sixth week of antiviral therapy with valganciclovir, a drug used to treat closely related cytomegalovirus (HHV-5). Of note, the group also found that short-term treatment regimens, even up to three weeks, had little or no impact on the HHV-6 mRNA level.

The investigators assumed that the integrated virus had become reactivated in these patients; however, to their surprise, they found that these IHS patients were infected by a second unrelated strain of HHV-6.

The USF-led study was supported by the HHV-6 Foundation and the National Institutes of Health.

Further studies are needed to confirm that immune dysregulation, along with subsequent chronic persistence of the HHV-6 virus, is the root cause of the IHS patients' clinical symptoms, the researchers report.

Article citation: "Persistent human herpesvirus-6 infection in patients with an inherited form of the virus." Shara N. Pantry, Maria M. Medveczky, Jesse H. Arbuckle, Janos Luka,Jose G. Montoya, Jianhong Hu, Rolf Renne, Daniel Peterson, Joshua C. Pritchett, Dharam V. Ablashi, and Peter G. Medveczky; Journal of Medical Virology; published online July 25, 2013; DOI: 10.1002/jmv.23685

Patient information leaflets from the Chronic Fatigue Service at St Helier and Sutton hospitals

In our Autumn 2012 Newsletter we included an overview of the chronic fatigue service (CFS) at St Helier and Sutton hospitals. It's a multidisciplinary team (LMDT) and clinical network co-ordinating centre for people with chronic fatigue syndrome in southwest London and Surrey.

Under the leadership of Dr Amolak Bansal (Immunologist), the service teaches lifestyle management strategies (via combined bio-psycho-social and cognitive behavioural therapy) that help to manage symptoms, improve function and quality of life.

Epsom and St Helier NHS
University Hospitals
NHS Trust

The service provide associated patient information leaflets at the following link:

www.epsom-sthelier.nhs.uk/our-services/a-to-z-of-services/clinical-services/pathology/immunology/chronic-fatigue-syndrome/patient-information-leaflets