



Newsletter

Summer 2008



Future events

Please note that both sufferers and carers are welcome at the following group events:

Afternoon meet – Friday 29th August - 3.30pm

The Weyside Pub - Millbrook, Guildford, Surrey, GU1 3XJ

The Weyside is just a ten minute walk from the centre of Guildford. Set in a beautiful location right on the riverside overlooking fields and trees this top class food house has a lot to offer.



Evening meet

Tuesday 23rd September - 7.30pm

'Inn on the Lake' - Ockford Road, Godalming, GU7 1RH

Fresh food, stylishly modern feel, minutes away from the London Road. The menu is simple and contemporary. Fresh fish, great steaks and spit roasted meats, also lighter options such as salads, pastas and fried pizzas.



From Guildford head towards Godalming on the A3100. The 'Inn on the Lake' is located at the end of Ockford Road on a roundabout on the left.

Afternoon meet

Friday 17th October - 3.30pm

The Bridge Barn Pub, Bridge Barn Lane, Woking, Surrey, GU21 1NL

Bridge Barn is an attractive pub located beside the canal, easily accessed from Junction 11 of the M25 close to Thorpe Arch.

Pub Meals served from various extensive menus. Bar snacks, range of wines. Tea and range of Costa Coffee.

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|--|--------|
| 1. Head northwest on A320/Chertsey St | 131 ft |
| 2. Slight right to stay on A320/Chertsey St
Continue to follow A320
Go through 8 roundabouts | 5.3 mi |
| 3. At the roundabout, take the 1st exit onto Wych Hill Ln | 0.3 mi |
| 4. At the roundabout, take the 2nd exit onto Trigg's Ln | 0.3 mi |
| 5. At the roundabout, take the 3rd exit onto Goldsworth Rd | 0.2 mi |
| 6. At the roundabout, take the 1st exit onto Bridge Barn Ln | 420 ft |

Afternoon meet

Thursday 30th October - 3.30pm

The Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ

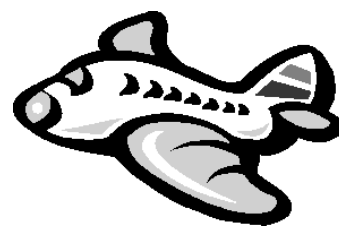
The hotel, which has plenty of parking, is near the Royal Surrey County Hospital. At the roundabout before the hospital, turn left into the hotel car park. They have a large foyer area with plenty of comfortable sofas and large coffee tables.



From M25: take junction 10 and follow A3 to Guildford and exit at exit sign for Research Park & Onslow Village. At 1st roundabout take 3rd exit. At 2nd roundabout take 2nd exit. From south: A3 to Guildford and exit signposted for Research Park and Onslow Village. At roundabout take 1st exit.

Vaccinations and pre-travel health care for ME/CFS sufferers

If you are well enough to start travelling outside the relatively safe area covering most of Europe, USA, Canada, Australia and New Zealand, where travel vaccinations aren't usually required, it's likely that you will need to consider the pros and cons of one or more vaccinations. There are a few exceptions to the general rule about 'safe countries'. For example the presence of tick-borne encephalitis in the warm forested areas of Central and Eastern Europe and Scandinavia and the re-emergence of diphtheria in parts of the former USSR.



There are reports describing how various vaccines have triggered or exacerbated pre-existing ME/CFS, but if someone with ME/CFS starts travelling to countries where specific vaccinations are strongly advised or even made compulsory with a certificate, as with yellow fever, it is essential for you to think carefully about where you are travelling and how to protect yourself against serious illnesses. You should also discuss travel to foreign countries and the vaccinations which may be required, thoroughly with your GP or health care professional.

Travel vaccinations often require more than one appointment at your GP surgery in order to complete a course. But as with any vaccination and ME/CFS, they should normally be deferred if you are:

- in the very early stages of ME/CFS, particularly when it has obviously followed an infective episode;
- having a lot of flu-like symptoms, including sore throat, enlarged glands, fevers and joint pains, or a relapse of other ME like symptoms; or
- worried that you have previously experienced an adverse reaction to that particular vaccine.

A course of travel vaccinations should, wherever possible, be planned to be completed at least two weeks before departure – in case side effects occur.

Obtaining reliable information

You shouldn't leave this aspect of pre-travel health care to the last minute. It is well worth checking on vaccination advice before even making a booking – just in case you don't want to proceed. Travelling to an exotic location without proper protection is very risky.

Thanks to the internet it is now very easy to locate accurate and up-to-date advice about health requirements for overseas travel. Sites such as Fit for Travel (www.fitfortravel.nhs.uk), netdoctor (www.netdoctor.co.uk) and Medical Advice Services for Travellers Abroad/MASTA (www.masta.org) provide sound advice on food, water, general hygiene, risks from specific infections, and appropriate methods of protection on a country-by-country basis.

Some GP surgeries now run special travel clinics where advice can be obtained and arrangements made for whatever vaccinations, anti-malaria pills etc. are going to be required.

Advice contained in travel company brochures, and from travel agents, about health requirements abroad can be inaccurate and should not be relied on. Homeopaths and other complementary practitioners may recommend other forms of protection but there is insufficient evidence of effectiveness to recommend their use.

Vaccines that may be recommended or required

Some vaccines are contraindicated in people who have evidence of immune system suppression or an allergy to eggs – this should always be mentioned when deciding if a vaccine is appropriate.

All vaccines are capable of producing side-effects – fairly common ones include fever, fatigue, headache, joint pain, rashes – but these are normally limited to a few days. Fortunately, serious reactions, including neurological ones, are far less likely but can occur with vaccines such as the one for yellow fever.

So the decision on whether or not to have a particular vaccine has to take common sense into account as well as the official printed guidance – which may not allow for a sensible degree of flexibility. For example, where rabies is present, vaccination would be vital for someone travelling to remote areas away from medical attention, but may not be necessary if the stay is being confined to a hotel.

Anyone who has ME/CFS should discuss travelling abroad and vaccinations thoroughly with their GP or specialist before making their decision.

Specific vaccines

Cholera

Oral cholera vaccine (Dukoral) does not provide complete protection. As with typhoid, scrupulous attention to food, water and personal hygiene is essential.



Hepatitis A

This infection can cause a severe relapse of ME/CFS symptoms. It can also trigger ME/CFS in previously healthy people. Outbreaks of hepatitis A occur quite frequently in less developed countries – even in hotels and holiday resorts. Long lasting protection is now available and there has been very little feedback about adverse reactions from people with ME/CFS who have had this vaccine. Nevertheless, you should discuss the possible side effects with your GP or healthcare professional.

Polio

A list of countries with a high incidence of polio can be obtained from www.travax.nhs.uk. There is no evidence that people with ME/CFS have problems with the polio vaccine but you should discuss possible side effects with your GP or healthcare professional.

Tetanus

Up to date protection would be important if you are taking part in activities that could involve exposure to tetanus infection. Tetanus is caused by a bacterium which lives in soil and manure.

Typhoid

The best way of protecting against typhoid is to avoid taking risks with food and water that may carry the infection. Sensible self-help advice can easily be found elsewhere. The typhoid vaccine is only around 70% effective – so food hygiene is essential as well. An oral typhoid vaccine (Vivotif) is also available. The typhoid vaccine (by injection) can produce side effects in healthy people, however feedback received from ME/CFS patients indicates that the oral form of the typhoid vaccine is generally well tolerated. Do discuss thoroughly with your GP or healthcare professional though.

Yellow Fever

This is a potentially fatal infection that is present in parts of Central and South America and parts of the Caribbean. Countries affected are likely to require an International Certificate of Vaccination. Surrounding countries may also require a certificate if you have recently travelled through a country at risk. So a careful check needs to be made on vaccination requirements well before departure. Officially recognised protection lasts for 10 years. Side-effects include headache, fever, fatigue and stiffness, which may occur 4-7 days after vaccination. Other less common side-effects include muscle pain, enlarged glands and a rash. Neurological complications such as meningoencephalitis and an unusual multi-system illness have been reported.

Up to date protection against **Diphtheria and Tuberculosis** may be necessary in some countries so do look into this. For travel to more exotic locations, particularly in Africa, the list of recommendations may be quite long and include vaccination against **Rabies, Meningitis and Encephalitis**.

Malaria

There are various anti-malarial drugs available on prescription. These drugs normally have to be started before entering an at-risk country and continued after leaving. Simple self-help measures – effective insect repellents, covering up exposed areas of skin, use of impregnated mosquito nets at night – are also very important.

Using the right drug or combination of drugs, on a regular basis is absolutely vital, so do obtain accurate, up-to-date information on which drugs are currently being recommended for the country you are visiting.

Lariam, also known as mefloquine, is very effective but needs to be used with caution (or not at all) if you have had neurological or psychiatric health problems.

Other pre-travel health care information

Heat

Sensitivity to changes in temperature are a common feature of ME/CFS, so it's worth checking what the weather and humidity is going to be like in more exotic locations if you are already heat sensitive. It's also worth noting that some types of medication (e.g. antidepressants) have a potential to exacerbate this problem.

Medication

Make sure that you have an adequate supply of any regular medication and keep a separate written list of the names of any important drugs in case anything goes missing.

Traveller's diarrhoea

The most common cause of illness amongst travellers is diarrhoea, which is often caused by bacteria. One of the most effective ways to avoid traveller's diarrhoea is to 'boil it, cook it, or forget it' when it comes to the local food. The most important self-help form of treatment for diarrhoea is rehydration: replacing lost fluids, using an oral rehydration salt such as Dioralyte.

A drug called loperamide (available over the counter) will quickly help to stop very loose bowel movements – but do read the cautionary notes in the instructions. Some doctors also advise taking a single dose (possibly continued for three days) of an antibiotic such as ciprofloxacin for a more severe attack – but you will need a prescription for this.

Travel insurance

Failure to take what are regarded as adequate precautions may cause problems with a travel insurance policy if a claim has to be made. Hospitalisation from a serious infection such as malaria or yellow fever could easily run up an enormous bill. The ME Association has a separate leaflet covering travel insurance and their head office has a list of insurers who are generally sympathetic towards insuring people with ME/CFS.

The Department of Health booklet 'Health Advice for Travellers' includes information on vaccination requirements or recommendations around the world. The booklet can normally be obtained from travel agents, post offices, or by phoning 0800 555 777 (24 hour service). It is also available on the internet at www.dh.gov.uk

This information was obtained from articles written by Dr Charles Shepherd, medical adviser to The ME Association. It is not intended to be a substitute for medical advice or treatment from your doctor. You should talk in depth to your GP or health care professional before travelling to foreign countries and/or making decisions re vaccinations.

Protein from a common smoldering virus linked to CFS and depression

by HHV-6 Foundation 06-23-2008

Source: <http://www.chronicfatiguesupport.com/library/showarticle.cfm/id/8946>

HHV-6 Foundation reports on a groundbreaking presentation at the' International Symposium on Viral Infections in CFS'.

BALTIMORE, MD, June 23, 2008 - A study suggests that a "smoldering" central nervous system (CNS) infection may play a role in conditions that plague millions of Americans.

Kazuhiro Kondo, MD, PhD, of the Jikei University Medical School in Tokyo, identified a novel human herpesvirus-6 (HHV-6) protein present in Chronic Fatigue Syndrome (CFS) patients but not healthy controls that may contribute to psychological symptoms often associated with that and other disorders.

"Causes of many chronic diseases are unknown and chronic viral infection is one of the most suspected candidates," said Dr. Kondo, who spent 20 years trying to identify the latent protein responsible for chronic CNS disease and mood disorders.

Support for Dr. Kondo's claim came from Stanford University's Jose Montoya, who announced at the same conference that the antiviral drug Valcyte [valganciclovir], shown to be effective against HHV-6, resulted in an improvement in the cognitive functioning of CFS patients, although not a complete resolution of their fatigue.

According to Dr. Kondo, drugs like Valcyte combat active replication but can't completely control low-level smoldering. "To cure the diseases, we have to reduce the latently infected virus or prevent its reactivation," he explains.

A debilitating disorder

Chronic Fatigue Syndrome is a debilitating disorder affecting one to four million Americans and causing 25 billion dollars a year in economic losses. The primary symptoms include post-exertional malaise, fatigue, difficulty concentrating, unrefreshing sleep, muscle and joint pain. High rates of depression co-occur with the disease.

Mostly striking working-age adults, the disease is often triggered by a flu-like episode. Efforts to find a single pathogen responsible for the disease have, however, failed and the cause of the disorder is unknown.

Novel herpesvirus protein is associated with altered nervous system cell activity and CFS and Depression

Kondo identified a novel HHV-6 protein associated with latent (non-replicating) HHV-6-infected nervous system and immune cells. Transfecting this new protein, called SITH-1 (Small Intermediate Stage Transcript of HHV-6), into nervous system cells called glial cells resulted in greatly increased intracellular calcium levels. Increased intracellular calcium levels are believed to play an important role in psychological disorders and can contribute to cell death. Expressing the SITH protein through the use of an adenoviral vector in mouse resulted in manic-like behavior.

A serological study indicated that 71% of CFS patients with psychological symptoms - and none of the healthy controls - possessed the antibody against the SITH-1 protein ($p < .0001$).

Further tests indicated that 53% of depression and 76% of bipolar depression patients possessed the antibody.

Traditional viral tests may overlook important disease causing processes

Researchers have suspected that central nervous system infections could contribute to psychological and central nervous system disorders, and patients with CFS have a much higher than average rate of depression.

This virus spreads cell-to-cell instead of releasing viral particles into the bloodstream. This has hampered efforts to demonstrate that the virus plays a role in CNS disease. "This virus persists in the brain and other tissues, but not the blood, which is where investigators have looked," says Kristin Loomis, Executive Director of the HHV-6 Foundation. "Indeed, standard serum PCR DNA for direct evidence of the virus are useless," she added.

New ultra-sensitive assays are under development, she reports, "but currently the best way to identify patients with smoldering HHV-6 infection is to look for elevated IgG antibody titers."

Dharam Ablashi, the co-discoverer of the HHV-6 virus, and the HHV-6 Foundation's Scientific Director, warns that the test won't be available in the near future. "It may take years to get the assay validated and into commercial production, but will be worth the wait," says Ablashi. "This assay could identify large numbers of patients with CNS dysfunction who could benefit from antiviral treatment. The HHV-6 Foundation is working hard to help scientists like Dr. Kondo develop better assays."

The HHV-6 Foundation

The HHV-6 Foundation encourages scientific exchanges and provides grants to researchers seeking to increase our understanding of HHV-6 infection in a wide array of central nervous system disorders. Contact: Kristin Loomis, Executive Director HHV-6 Foundation
<http://www.hhv-6foundation.org/> Phone: 805-969-1174

Note: This information has not been evaluated by the FDA. It is generic and is not meant to prevent, diagnose, treat or cure any condition, illness, or disease. It is very important that you make no change in your healthcare plan or health support regimen without researching and discussing it with your professional healthcare team.

Southampton conference DVD

A DVD-set of the proceedings of the Southampton ME/CFS biomedical research conference on 12 February is now available.

Copies of the DVD set will cost £20 each and may be ordered from:

The Alliance for Fibromyalgia, ME/CFS, P.O. Box 558, Winchester, SO23 3FX
Cheques should be made out to The Alliance for Fibromyalgia, ME/CFS.

Alternatively, the group has obtained a copy of the DVD for the group's library. To borrow the group's copy please contact Cathy Gould by email: Catherineg_9@hotmail.com

The conference was hosted by Professor Stephen Holgate, professor of clinical pharmacology at Southampton University, who has just been named as chair of a new multi-disciplinary panel set up by the Medical Research Council which will focus on the subtypes and aetiology of ME/CFS as part of a plan to fertilise cross-disciplinary research activity in this field.

Other speakers included co-chairs Professor David Peters and Professor Paul Little, Professor Martin Pall, Dr Jonathan Kerr, Dr Russell Lane, Dr Byron Hye, Dr Estabiliz Olano-Martin, Professor Malcolm Hooper, Professor Hugh Perry, Dr Charles Shepherd, Professor Rona Moss-Morris and Dr Sarah Myhill.

Brian Aldiss, the doyen of British science fiction writers whose writing career came close to being wrecked by ME 30 years ago, also spoke at the event. Neil Riley, chairman of The MEA Association, hoped to – but sudden illness prevented his attendance. Instead, Neil has now recorded his speech which is also included in the DVD set.

What is this life if

By Patricia Martin – ex-newsletter editor of the Guildford ME Group

"What is this life if, full of care, we have no time to stand and stare, " wrote the poet, William Henry Davies. Journalist Patricia Martin, who was struck down by ME in 2001, feels there are some compensations.

If I think about it, I'm not really surprised that I have a chronic debilitating illness. I believe that if you have certain genes, burning the candle at both ends for many years will result in illness of some kind. Severe stress can damage the immune system - it is your body's way of forcing you to slow down.



In the past, I led a full, exciting life but had little quality time to notice things that really mattered - like how fast my daughter was growing up, how my mother was ageing, and certainly, in the poet's words: "No time to turn at Beauty's glance, And watch her feet, how they can dance." I was too busy dancing myself!

After training as a journalist on a Surrey newspaper, I got married, had a daughter, and subsequently got divorced. I became a Press Officer, working initially in Local Government and later at Guildford's Yvonne Arnaud Theatre. Life as a single mum was hectic but somehow I managed to fit in Morris dancing for several years.

When WWF-UK moved its headquarters to Surrey, I began a 20 year career in media work for national charities. Subsequently, with Oxfam and Christian Aid, I travelled all over the world reporting on famines and development projects. The trips were amazing, humbling - but also hard work and stressful. Finally, after my mother had a stroke, I tried to slow down by working part-time, but in reality I was still doing a full time job, plus commuting.

The new Millennium was approaching - my partner and I decided to tie the knot after 19 years together; Sadly, my mother had died, and my father was wheelchair-bound in a care home. Of course, I visited him regularly. We had two little grandsons by then as well.

I took over running a multi-media team while my boss went on maternity leave, but couldn't find a replacement for myself. Ended up doing two jobs, running a big millennium project with Channel 4, as well as organising our wedding. It was all too much of course. I started getting panic attacks and infected eczema, never before experienced. I felt tired all the time, struggled to do the long walks I had always loved. I was under severe stress, mostly exciting and enjoyable, but I couldn't get off the treadmill.

In the New Year of 2001, a burst blood vessel in my right eye permanently damaged my sight. Soon after, my father was rushed into hospital with a chest infection, which I caught - he died, while I was too ill to visit him. I have never really recovered physically from that. Had to give up my job, though continued freelancing. Initially diagnosed with "post-viral fatigue", after one year diagnosed with ME. The illness led to my husband taking early retirement ' we had to move from our beloved home in Surrey to Sussex - causing further stress and making my illness worse.

Last year, I tried some treatment with an Eastbourne -based alternative doctor, involving an anti-candida diet, followed by consuming a large number of supplements to kick-start my energy levels. (A blood test showed I could make energy normally, but was unable to use it up.) I think the treatment helped - though the tablets caused IBS- but I can't be certain, as it coincided with the beginning of a much more settled life.

Continued on the next page...

The good news is, I think I've stabilised now - so long as I pace carefully (absolutely vital). Fybogel Mebervine sachets have settled the stomach. We are living happily in Seaford, and I have learned to accept my limitations. Being housebound five days a week, I have adapted my hobbies - wildlife watching, always a joy, is now confined to the garden, and I've taken up tapestry and greeting card design; I belong to a Book Group, and have started writing a children's novel.

I have been blessed by the loving support of my husband, family and friends. Of course I struggle most of the time, and long for a return to good health, but I do have time now to stand (or shall I say, sit) and stare. I notice how evening sunlight lights up the apple blossom; see sparrows taking a dip in our pond; hear and glimpse sheep and lambs on the Downs; photograph purple and pink sunsets.

"A poor life this if, full of care, we have no time to stand and stare" writes William Henry Davies in his final verse. And yes, I agree with that - but I do miss the dancing!

D-ribose

The following exert from a leading self-improvement website provides an insight into a possible reason why D-ribose is popular in ME circles.

People with disease-induced energy deficit disorders -- such as chronic fatigue syndrome, fibromyalgia, Lyme disease, MS, lupus, AIDS and many others -- are actually being robbed of their vital energy by the disease process itself. In the case of chronic fatigue, it is believed that the Epstein Barr virus or some other pathogen such as mycoplasmas actually infiltrate and attack the body's cells. These pathogens severely damage the ability of the cellular mitochondria to produce sufficient amounts of ATP. Of course, ATP is the body's chief energy molecule. Since literally hundreds of millions of cells can be damaged or compromised by an underlying infectious illness, the remaining undamaged cells are left with the task of trying to produce enough ATP to fuel the entire body. It's like an eight cylinder car running on only five or six cylinders. The body simply becomes weaker and weaker over time, because the damaged cells are functioning at excessively low levels, and the undamaged cells are being taxed to their limits. The disease process spreads, because the cells cannot produce enough energy to empower the body to fight it off.



Fortunately, by supplying the body with supplemental D-Ribose -- basically flooding the cells with the nutritional fuel they need to produce dramatic levels of extra energy in the form of ATP - you can frequently "jump start" the body back into high gear. The immune system gets the energy it needs to begin functioning at peak levels again. The brain gets the energy it needs to direct the healing process. Neurons fire better, not just in the brain but throughout the entire nervous system, sending healing chemical and electronic messages throughout the body with lightning speed. Synaptic transmission is restored to peak function. There is even some evidence that the cells damaged by the pathogens begin to recover when given the fuel they need for self-repair. And finally, energy levels are fully restored, and the body is able to pull itself out of the downward spiral caused by the underlying disease process.

Source:

http://www.selfgrowth.com/artman2/publish/altmed_articles/4_Powerful_Ways_to_Maximize_the_Energy-Boosting_Benefits_of_D-Ribose_printer.html

D-ribose is available from online health supplement suppliers such as www.vitmainuk.com and www.iherb.com (American site good for discount bulk buying, subject to additional 17.5% vat and brokerage charge e.g. £10 at door upon delivery using ups or by separate bill using DHL).

Further related reading: <http://www.drmyhill.co.uk/article.cfm?id=381>

Disability rights at work...

By Penny Drage – Camberley Disability Employment Adviser (Tel: 01276 893951)

If you are experiencing difficulties at work due to health problems or disabilities, your first port-of-call should be your line manager. It doesn't matter if the problem is newly acquired or due to a deteriorating condition.

A good management team should be fully aware of the Disability Discrimination Act, what this means to their firm and how to support their staff along with their HR department.

Unfortunately, this is not always the case. The act says that "reasonable adjustments" must be made for people whose health problems "substantially affect their day to day life." What this means in one instance may be quite different in another. It may be necessary to seek advice and this could come from a number of sources:

- The DDA helpline (Tel 0845 6046610) is run by the Disability Rights Commission and they can advise in individual cases.
- The Advisory Conciliation and Arbitration Service (ACAS) (Tel 0845 7474747) is another possibility. They can advise on general industrial relations.
- ACAS suggested calling the Equality and Human Rights Commission who put callers through to a specialist depending on the help required. Their contact details are www.equalityhumanrights.com Tel 0845 7622633 or 0845 6046610.

Another useful area of support is the Disability Employment Adviser at your local Jobcentre. The DEA can advise you or your employer of any "reasonable adjustments" that could be made, ranging from a change or reduction of hours, change of duties or role, useful equipment, in work support or even working from home.

They can also inform you about the Department of Work and Pensions Access to Work scheme which provides specialist equipment, such as enlarged software or voice activated systems for those with visual impairments or lumbar support chairs.

The Access to Work scheme also, amongst other things, helps with support workers who take on parts of a job that the disabled person can no longer cope with, fares to work and Interpreters for hearing impaired staff.

FDA accepts antiviral drug Ampligen for review as first-ever ME/CFS ('chronic fatigue syndrome') therapeutic

July 8 2008– After 30 years in development and testing, the experimental "antiviral/immune modulatory" drug AmpligenR has been accepted by the FDA for review as potentially the first prescription drug approved in the U.S. for treatment of ME/CFS – specifically for certain patients with severe ME/CFS. Delivered intravenously, typically twice weekly over a year or more, AmpligenR (AMPLified GENetic activity) has been available in Belgium and Canada for ME/CFS and HIV treatment since 1996.

AmpligenR - still allowed only in specific clinical trial settings conducted under U.S. governmental authorization - is termed "a nucleic acid drug," designed to "modulate" the body's immune system. Its mechanism of action in ME/CFS "is not entirely clear," but it is thought to act on two enzyme systems so as to help the immune system destroy viral RNA and speed the death of virus-affected cells. In particular it may "downregulate" an anti-viral pathway which research suggests has become "upregulated" in certain ME/CFS patients (the 2-5 Synthetase/RNase L anti-viral pathway).

The drug's maker – Philadelphia-based Hemispherx Biopharma, submitted a New Drug Application to the FDA in 2007, and had been asked to answer a series of questions. The FDA's acceptance of the drug for safety/efficacy review was based on receipt of the requested data. The maker reportedly suggests it is also researching oral delivery of the drug. A "Who's-Who" of the world's leading ME/CFS specialists have participated in AmpligenR trials over the years.





Ten Discoveries about the Biology of CFS

- 1** Chronic fatigue syndrome is not a form of depression, and many patients with CFS have no diagnosable psychiatric disorder. As with most chronic illnesses, some CFS patients become depressed because of the impact of the illness on their lives, but most studies find that the majority haven't experienced depression before the onset of illness.
- 2** There's a state of chronic, low-grade immune activation in CFS. There is evidence of activated T cells, activation of genes reflecting immune activation and increased levels of immune system chemicals called cytokines.
- 3** There's substantial evidence of poorly functioning natural killer (NK) cells—white blood cells important in fighting viral infections. Studies differ as to whether there may be increased numbers of NK cells in CFS patients.
- 4** Abnormalities in the white matter of the brain have been found in CFS patients using magnetic resonance imaging (MRI) scans. Typically, these are small (fraction of an inch) areas just below the cerebral cortex, the outermost area of the brain hemispheres. Differences in gray matter volume are also being observed.
- 5** Abnormalities in brain metabolism, as indicated by single photon emission computed tomography (SPECT) and positron emission tomography (PET), have been discovered. Other research suggests there's something wrong with energy metabolism and the oxidative electron transport chain in the mitochondria of CFS patients.
- 6** CFS patients experience abnormalities in multiple neuroendocrine systems in the brain, particularly depression of the hypothalamic-pituitary-adrenal (HPA) axis, but also the hypothalamic-prolactin axis and hypothalamic-growth hormone axis.
- 7** Cognitive impairment is common in CFS patients. The most frequently documented abnormalities are difficulty with information processing, memory and/or attention.
- 8** Abnormalities of the autonomic nervous system have been found by numerous independent researchers. These include a failure of the body to maintain blood pressure after a person stands up, abnormal responses of the heart rate to standing and unusual pooling of blood in the veins of the legs. Some studies also find low levels of blood volume.
- 9** CFS patients have disordered expression of genes that are important in energy metabolism. Energy comes from certain natural chemicals that are processed by enzymes inside each cell. These enzymes are controlled by specific genes. Other genomic research is revealing involvement of genes connected to HPA axis activity, the sympathetic nervous system and immune function.
- 10** There's evidence of more frequent latent active infection with various herpesviruses and enteroviruses. The herpesviruses include Epstein Barr, HHV-6 and cytomegalovirus. Other infectious agents, like bacterium that cause Lyme disease, Ross River virus and Q fever, can also trigger CFS.

The above summary of CFS research findings was provided by Anthony Komaroff, MD, a professor of medicine at Harvard Medical School, senior physician at Brigham and Women's Hospital in Boston and the editor-in chief of Harvard Health Publications. Dr. Komaroff has an ongoing research program on chronic fatigue syndrome and has published over 230 research articles and book chapters.



The CFIDS Association of America