Guildford M.E. Support Group

# Newsletter

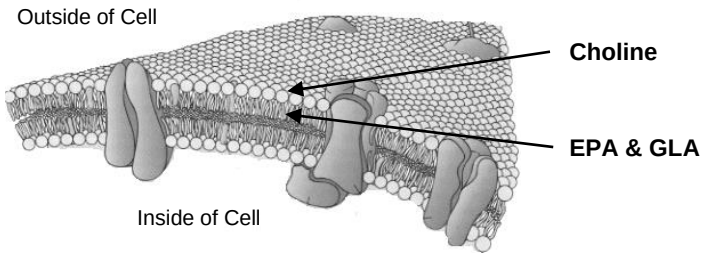
## Winter 2006

## Professor Puri explains EPA/GLA therapy

On the 29th October leading researcher Professor Puri provided a free lecture, at Guildford College, on his research into M.E. and explained how supplementation with EPA and GLA fatty acids offers sufferers a potential therapy.

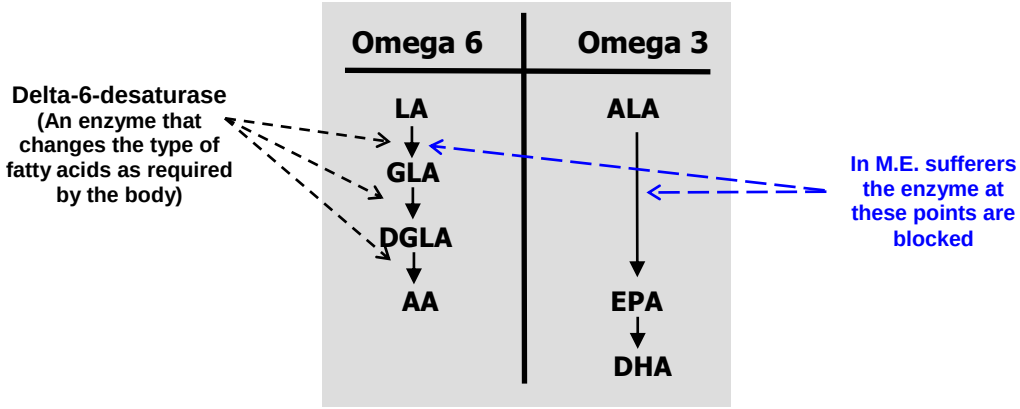
Thanks to Alison Wallis – our Publicity Officer, who organised and advertised the event, a large audience of sufferers and carers learned the science behind Professor Puri's discovery.

By using Neurospectroscopy imaging (similar to an MRI) Professor Puri discovered very high levels of Choline in the brains of M.E. sufferers. Knowing that Choline is usually combined with EPA and GLA by the body to form the membrane (outer shell) of human cells, Professor Puri deducted that M.E. sufferers are not able to create the levels of EPA and GLA fatty acids in their bodies that healthy people do, resulting in many biological difficulties that we know as M.E.




Without sufficient fatty acids, cell membranes become more rigid and the reduced flexibility is reflected in poorer or abnormal functioning of receptors that lie in the membranes, which in turn means that communication between cells, including brain cells, is impaired.

Professor Puri explained that our bodies use enzymes to create EPA and GLA and that certain viruses, nicotine, caffeine and stress can stop these enzymes working, as represented in the diagram below. By taking EPA and GLA supplements, M.E. sufferers restore the healthy levels of these fatty acids in their body, reversing M.E. symptoms and potentially repairing the body's ability to create its own EPA and GLA.




The typical supplement for EPA is Fish Oil and is available in tablet form from a number of manufacturers. Professor Puri explained that, typically, in addition to EPA, Fish Oil also contains DHA (a fatty acid that prevents the EPA from working correctly). Further, unless Fish Oil is treated with specialist filtering, it will contain toxic substances that the fish picks up from the environment.

As such Professor Puri recommends a supplement called "VegEPA" that contains no DHA and has been heavily filtered to ensure the purity of the EPA. VegEPA also contains the required GLA. An in-depth overview of VegEPA is available from the following website www.vegepa.com


VegEPA can also be ordered, at a discounted price, from: http://www.thevegepaformescheme.com

## Co-factors

Professor Puri explained that, in addition to supplementation with EPA and GLA (via VegEPA) it is important that a number of co-factors are also present to assist with the processing of fatty acids in the body. The most important co-factors are: folic acid, vitamin B12, vitamin B6, niacin, biotin, vitamin C, zinc, selenium and magnesium. All of which are present in a quality multivitamin supplement.

## Not all in the mind

To further expel the myth that M.E. is all in the mind, Professor Puri detailed a number of abnormal findings commonly found in M.E. patients. These included: enlarged lymph glands, an enlarged liver (Hepatomegaly); detectible changes in the immune system (decreased NK activity and Th1 levels, increased Th2 and Te); detectable changes in the blood fatty acid levels (decreased AA and EPA) and changes in gene expression in blood cells. Professor Puri stated that the best explanation for the pattern of results seen in M.E. is that there is a pre-existing long-term viral infection, to which the immune system is reacting.

## Contact Professor Puri to test you

Professor Puri welcomes requests from M.E. sufferers to participate in his on-going research at the Hammersmith Hospital in London. His only condition is that you have been officially diagnosed with M.E. according to the CDC 1994 Fukuda definition (the commonly used criteria for diagnosing M.E.).

If interested, please write to Professor Puri at the following address:
MRI Unit, Hammersmith Hospital, Du Cane Road, London W12 0HS

## Relaxation techniques

Relaxation techniques to help reduce stress that were mentioned include: CBT, Exercise (walking, slow cycling or swimming), Massage therapy, Aromatherapy, Reflexology, Daoyin Tao, The Alexander Technique and the Perrin Technique (see page 5).

## Professor Puri BChir, MB, MRCPsych, PhD, MMath, DipStat

Professor Basant K. Puri gained his primary medical degrees at Cambridge University and then went on to train in Cambridge and London. He is now Professor and Consultant at Hammersmith Hospital (London) and Head of the Lipid Neurosciences Group at Imperial College London.

For the last five years, Professor Puri has been using natural fatty acids at Hammersmith Hospital (London) to treat patients with Attention Deficit Hyperactivity Disorder (ADHD), Depression, Fibromyalgia and Huntington's Disease, as well as other brain disorders like Schizophrenia and Chronic Fatigue Syndrome (also known as M.E.). His treatment approach and research findings have been published in authoritative medical journals and he has given many talks at international medical conferences, as well as appearing on BBC and Sky News and BBC 2's flagship science series, Horizon.

Professor Puri's research into elevated choline levels in the brain of M.E. sufferers has been repeated with confirming conclusions by Tomoda (2000) and Chaud Huri (2003).

# Our Christmas dinner photo

# Future events

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

## Coffee morning - Friday 23rd February (11am – 1pm)

Egerton Road, Guildford, GU2 7XZ

The Holiday Inn hotel, Guildford. 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. We will display a sign so that you can find us easily.

**Directions**

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.

## Afternoon get together – Saturday 31st March (2pm)

The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU

Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham). The Seahorse Inn is on the right before you reach the station.

# Important note concerning yearly subscriptions

Can we please remind you of how important the yearly subscriptions are to the running of the group. The majority of the money is used to print and post the newsletters. At the moment, we are posting out approximately 100 newsletters per quarter and e-mailing another 80+. Unfortunately, we have only received 60 subscriptions since March of 2006, which means that our bank balance will soon drain away.

There maybe a number of members on our database who no longer wish to receive the newsletters. We have therefore decided that this is the last newsletter that we will send to all 180 members. The next copy will only be sent out to those members who are up to date with their subscriptions.

The subs for 2007 are not due until April, so many thanks to those of you who have paid. Please send any previous year's subs (£5.00 made payable to The Guildford ME Support Group) to Cathy Gould at Westdene, Elmbridge Road, Cranleigh, Surrey, GU6 8NW. Telephone 01483 277790 or email at catherineg_9@hotmail.com for further information. Many thanks for your continued support of the group.

# It worked for Me

**For our on-going column "It worked for me", our Publicity Officer, Alison Wallis, has kindly written an overview of her M.E. experience and in particular tells of the significant improvement she has experienced via use of VegEPA – as overviewed on page one and two of this newsletter.**


I have had ME for just over three and a half years and, like most people with ME, have tried various treatments; some helped some didn't. I was initially helped by complex homeopathy (very different to the usual homeopathy) where a machine was used to detect what parasites, viruses and bacteria I had in my body and then the relevant remedies given to clear them. This system is used in Germany and in the Netherlands for a variety of conditions and many hospitals use it.

I also decided to go to the Breakspeare Hospital in Hemel Hospital which is a hospital for environmental diseases. I had a load of tests and the conclusion was, yes I did have ME and yes, I was short on vitamins and natural fatty acids, and yes I probably did have loads of allergies/sensitivities. They also discovered that both my peripheral and central nervous systems had been damaged by "probably a virus". Their answer was to offer treatment to me for the sum of around £10,000 which involved a three week detox in their day hospital, allergy testing and a large number of supplements - and of course no guarantee that it would work. Maybe this treatment has helped some people but I was extremely sceptical and decided not to go for it other than buy some of their supplements.

About a year and a half later I had improved but still had relapses/flare ups which lasted anything up to two months. I went on the local PCT course with a psychologist, physiotherapist and an occupational therapist. We were asked to write thought diaries, activity diaries and taught how to pace more effectively. I found this very helpful and I felt much more confident that I would improve and I gradually started to try to do more.

Just before the course finished my husband saw an article in the Times about Professor Puri's work on CFS/ME where he recommend taking VegEPA. I ordered the book relating to the article and read bits and pieces of it (I was still finding it hard to concentrate on any book at that stage due to brain fog). I took four capsules in the morning and four in the afternoon. At this stage I had all but stopped my other supplements as they were expensive and I really didn't know how much good they were doing me. After about three months I noticed that I had been feeling a bit stronger and, at last, I was able to read properly again and the brain fog had pretty much cleared completely.

I took the same number of VegEPA capsules for the next 5 months. I was not sure whether I should continue with such a high dosage and contacted Professor Puri by email. He replied the same day saying that it certainly would not do any harm to continue at 8 a day, but that some people reduce the dosage to 4 or 6. I found him to be very approachable and keen to help – always nice to meet somebody who is actually interested in ME!

I decided to go down to 4 a day and I continued to improve. I know that a few people are concerned that Professor Puri's talks are often sponsored by the drug company who makes VegEPA but I think one needs to remember that he does truly believe in the research he is carrying out; that came over in the talk. He has problems in receiving any money at all from the various funding organisations and if Igennus can help him make people with ME more aware of the research he is carrying out, then so much the better. He hopes to begin his next trial in the next couple of months. It will be interesting to hear the results.

**Continued overleaf…**

I have now not had any flare ups lasting longer than ten days since April. Recently, when I was helping to organise Professor Puri's talk and probably slightly overdid it, I got a gum infection and had to take antibiotics. I then felt truly awful with all the old symptoms coming back and I thought I was possibly in for the long haul this time, but, surprise-surprise, two weeks later I felt so well I decided to try a set of tennis. Unfortunately I then damaged by Achilles tendon so cannot play for a while, but it is great to have a normal injury and not another weird symptom! At least now I can live my life in a more 'normal' way and although I still have to be careful I consider myself very fortunate to be where I am today.

# Blood test shows distinct promise as tool for diagnosing CFS

by Editor of ImmuneSupport.com
07-10-2006

Recent tests using spectroscopic blood serum analysis successfully sorted the blood of healthy subjects from that of diagnosed Chronic Fatigue Syndrome patients with a 97 percent accuracy rate, according to a study by virologists at Japan's Osaka University and Osaka City University School of Medicine.

First, the researchers analyzed the serum of 77 known CFS patients and 71 healthy subjects using a visible and near-infrared (Vis-NIR) spectroscopy analysis. (Spectroscopy arrays molecular energy frequencies along a spectrum to depict the composition of complex substances.)

They found that the CFS blood samples and the healthy samples seemed to produce two different profiles, or models.

Next, they ran a test to see if they could use these models to sort out CFS serum samples from healthy samples. Working with a masked group of 99 subjects, they found that the spectroscopy analysis correctly classified the blood samples for all 54 of the 54 healthy subjects, and for 42 of the 45 CFS patients.

The study report, "Spectroscopic diagnosis of Chronic Fatigue Syndrome by visible and near-infrared spectroscopy in serum samples," by Akikazu Sakudo, et al., is published in the July 14, 2006 issue of Biochemical and Biophysical Research Communications at www.sciencedirect.com.

# Gibson inquiry – November 2006

During 2006, a parliamentary level inquiry into the progress of scientific research on M.E. took place. In November, the report, lead by Dr Ian Gibson MP, was released.

The report is 35 pages long and contains concise information that is too extensive to summarise successfully within the scope of our newsletter. The report is extremely well written and manages to capture the salient issues of the current M.E. environment.

The report can be viewed on our website at: www.rescue.f2s.com or at the original source: http://www.erythos.com/gibsonenquiry/Report.html

# The Perrin Technique

The Perrin Technique™ was developed following a discovery in 1989 during the clinical practice of Manchester osteopath Dr Raymond Perrin. This osteopathic system of manual treatment alleviates many of the symptoms of M.E. and has cured many patients since 1989.
The treatment has been statistically validated in both clinical trials, emphasising the need to focus future research on the biomechanical aspects of this disorder. Raymond has expanded our knowledge of CFS/ME, which led to a doctorate awarded by the University of Salford.

The Perrin Technique is based on Dr Perrin's theory that different stress factors whether physical, allergies, emotional or infections lead to an overstrain of the sympathetic nervous system. Further investigation has led to a probable cause of this nervous system overload being a build up of toxins in the fluid around the brain and the spinal cord. Some of the poisons caused by infection or inflammation in the head or spine flow through perforations in a bony plate (the cribriform plate) just above the nasal sinuses into the lymph ducts of the face and neck. The toxins are also meant to drain down the spinal cord and out into the lymph ducts lying along the spine. In an M.E. sufferer, these normal drainage points are congested.

## Treating M.E.

The sympathetic nervous system spreads throughout the entire body affecting every type of tissue, but more importantly receiving messages from all the tissues e.g. skin, muscle, blood vessel, gland, lymph vessel etc. The latter forms an important network of small channels carrying lymph, which is a transparent bodily fluid collected from all tissues and eventually returned to the blood. The lymphatic system is basically a secondary waste disposal unit within the body which flushes out the waste products of the cells and foreign bodies that are toxic to us. The fluid motility in the lymph is helped by pressure from the blood flow in the surrounding blood vessels, and so the lymphatic tissue will be engorged with fluid if the blood circulation is not working properly. The sympathetic nerves also have been found to control a pump mechanism within the main drainage of the lymphatic system, which becomes disturbed in CFS/ME. The resultant backflow further engorges the lymphatic vessels, especially in the chest and neck.

The Perrin Technique™ is an osteopathic approach that manually stimulates the fluid motion around the brain and spinal cord. Manipulation of the spine further aids drainage of these toxins out of the cerebrospinal fluid. Massage of the soft tissues in the head, neck, back and chest direct all the toxins out of the lymphatic system and into the blood, where they are eventually detoxified in the liver.

Eventually, with no poisons affecting the brain, the sympathetic nervous system begins to function correctly, and providing the patients do not overstrain themselves their symptoms should gradually improve and in time some patients become totally symptom free.

## Further information

Refer to the following website: www.theperrinclinic.com

## Local practitioners

The Southsea Centre for Complementary Medicine
Laurent Heib DO, 25 Osborne Rd, Southsea, Portsmouth, PO5 3LR Tel: 023 9287 4748
E-mail:sphenoid1000@yahoo.com

The Point of Health
Mr Laurent Heib D.O., 106 Winchester Road, Chandlers Ford, Eastleigh, Hampshire, SO53 2GJ
Tel: 023 80269809

# Potential medical treatments ?

The following summaries of medical treatments relevant to M.E. have been taken from the MEActionUK website at the following website address: http://www.meactionuk.org.uk/treatments.html Additional treatments from the same source will be included in our following newsletters.

## Introduction

No treatment has been proven to benefit patients with M.E. in large randomised controlled trials that have been replicated by other investigators in other populations of patients. However, many small-scale clinical trials have revealed potential benefits from some drugs and supplements, mostly in terms of symptomatic treatment. As someone who has benefited consistently over several years from one such treatment, I hope that a summary of treatment options may be of help to someone else.

Del Kennedy

## Mycoplasma Treatments

Doxycycline, Azithromycin or Erythromycin

The role of mycoplasma infections in M.E. is presently a grey area. The hypothesis is that mycoplasmas infect immune-system cells, causing these transcriptional & translational problems, killing some cells, causing immune dysfunction and activating the T-cells.

It is possible that an already compromised immune system may be particularly vulnerable to this class of microbe. Many physicians consider it an unlikely candidate as the primary cause of M.E., but it may excacerbate symptoms.

The best treatment is doxycycline. Mycoplasmas take three months at least to eradicate. If you have a co-operative G.P., it could be worth a try, but don't forget the need to replace your gut flora with probiotics immediately afterwards.

## Neurontin

If your system can tolerate it, Neurontin can often restore cognitive function to a surprising degree.

Dr J. W. Seastrunk, a psychiatrist who worked with brain injuries for 30 years, has pioneered the use of this drug as a treatment for M.E.. In large doses, it does appear to be capable of producing a very marked improvement even in severe sufferers.

Neurontin was originally developed as an antispasmodic (muscle relaxant). But it also helps prevent neurones from misfiring. It is not yet understood exactly how it does this.

It is used in doses up to 6,000 mg per day, and is available on prescription. Some G.P.s are already prescribing it for the treatment of M.E., though most take a lot of persuading.

## Colostrum

In studies performed by the Wisconsin Viral Research Group, single random blood specimens from ME sufferers were obtained from clinics around the country, and 39 percent of the patients turned out to be positive for active HHV-6. Significantly, none of the blood samples from normal control subjects were positive, demonstrating that active HHV-6 infections in the blood are highly abnormal.

In 1999, trials were conducted on ME patients who were positive for active HHV-6 infection using a modified version of a treatment looked at earlier, using bovine colostrum. The treatment was run on 100 patients, half of which received a placebo. Statistically significant results were obtained, suggesting that Colostrum is a potential treatment for ME

Colostrum is the first milk from a cow that is present for 24-48 hours after the calf is born, and contains numerous immune-modulating components (antibodies, immune cells, transfer factors, and other immune-regulating proteins). This milk is very important to establish and maintain the immune system of a newborn.

To make a formulation helpful to ME sufferers, a company called Immunity Today uses a process in which expectant cows are injected with a form of the HHV-6 virus. Specific antibodies are thus included in the colostrum that the new-born calf receives. Their product is called Transfer Factor Formula 560.

## Gamma Immunoglobulin (IgG)

IgG contains antibodies to a broad range of common infectious agents and is ordinarily used as a means for passively immunising persons whose immune system has been compromised, or who have been exposed to an agent that might cause more serious disease in the absence of immune globulin. Its use with ME patients remains experimental; basically, there have been two papers that say it is useless and three papers that say it's helpful. If all else fails, and someone is very sick then they might get to try this. Privately, it is very expensive, from £500- £750 a dose and is given monthly.

## Enada (NADH)

NADH is known to trigger energy production by generating ATP (adenosine triphosphate) which stores energy in cells. If cellular levels of NADH are depleted, brain and muscle cells lose their ability to function effectively. The theory is that as NADH levels rise in the body, the cells become more energised, making the body feel stronger and more vitalised.

A good review of this promising treatment (available now without prescription) is already online at the about.com website

# Remember Me, a film by Kim A. Snyder

An award-winning documentary film about Chronic Fatigue Syndrome

**WINNER, Best Documentary, PEOPLES' CHOICE AWARD, DENVER INTERNATIONAL FILM FESTIVAL**
"A compelling documentary that combines heartbreaking and soul-stirring personal stories with investigative reporting about Chronic Fatigue Syndrome"

**Honorary Mention, Best Documentary, 2000 HAMPTONS INTERNATIONAL FILM FESTIVAL**
"A compassionate and inspirational documentary forged from the centre of the maelstrom, I REMEMBER ME is a step toward overcoming the healthcare industry's uncertainty, the government's scepticism and society's stigmatisation"

Fuelled by the same rage at an unresponsive system that has birthed many a great social documentary, filmmaker Kim Snyder has taken up the mantle for the many sufferers of Chronic Fatigue Syndrome (CFS). Afflicted with CFS herself, Snyder interweaves her own four years of fighting with the stories of others who face the same challenges.


Between May, 1984 and late 1986, over 300 people in Lake Tahoe, Nevada became acutely ill with a flu-like sickness. Over fifteen years later, many of them have not fully recovered, individuals across the country have become ill and the cause remains a medical mystery. Herein begins the bizarre tale of an elusive malady that in 1988 the US Centres for Disease Control named Chronic Fatigue Syndrome (a.k.a. CFS, CFIDS, ME).

I Remember Me is the first full-length documentary to explore the controversial and mysterious history of Chronic Fatigue Syndrome, an illness that, according to the CDC, is now forty times greater in prevalence than previously estimated. Once dismissed as Yuppie Flu, this mysterious syndrome, for which there is not yet a universally acknowledged cause or cure, has prompted fierce debate within the medical community.

"How do you come to know fact?" the filmmaker asks. Without scientific proof, she concludes "you're left with personal anecdote". So Snyder sets off on a four year journey to investigate.

Through the poignant testimonies of dozens of individuals -- including film director Blake Edwards (Pink Panther, 10), and Olympic gold Medallist and Women's World Cup Soccer star Michelle Akers, whose brilliant career was recently cut short by the illness, (set to the evocative music of legendary jazz musician Keith Jarrett, who was also sidelined by the illness for four years) -- a chilling human drama unfolds which continues to baffle scientists worldwide.

In her search for answers, Snyder unearths clusters of the illness dating back to 1936. Residents of a sleepy Florida gulf coast town are united forty years later to reflect on the illness that devastated hundreds of folks in 1956 and was never diagnosed. We hear strikingly similar accounts from local doctors in Incline Village, Nevada, the site of the original Lake Tahoe cluster, and Lydonville, New York, a rural upstate town where more than 200 people became ill in the mid-80's.

The story builds to an emotional climax as Steven, the severely disabled Connecticut teen, attempts to make his high school graduation by way of ambulance and gurney.

More than an account of an epidemic unfolding, I Remember Me speaks to the universal themes of loss, human perseverance and our difficulties in grappling with uncertainty.

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"I remember ME" is available to order from www.Amazon.co.uk and can be located on the site by typing in "I remember ME" in the DVD search box. If using an email version of this newsletter you can click on the link below. Please note that you will need a multi-region DVD player.

http://www.amazon.co.uk/I-Remember-Me-REGION-NTSC/dp/B00020X942/ref=sr_11_1/026-8569422-3682816

# Why all the names ?

An overview of the terms used for M.E., according to Wikipedia, is included below.

**Myalgic encephalomyelitis** (ME, "inflammation of the brain and spinal cord with muscle pain") as a disease entity has been recognised and described in the medical literature since 1938, with the seminal paper being that by Wallis in 1957; Sir Donald Acheson's (a former Chief Medical Officer) major review of ME was published in 1959; in 1962 the distinguished neurologist Lord Brain included ME in his textbook of neurology, and in 1978 the Royal Society of Medicine accepted ME as a distinct clinical entity.

In 1988, both the UK Department of Health and Social Services and the British Medical Association officially recognized it as a legitimate and potentially distressing disorder. Opponents to the term ME maintain there is no inflammation, although there are cases of CFS that present inflammation (see Sophia Mirza). United Kingdom and Canadian researchers and patients generally use this term in preference to CFS.

**Chronic fatigue syndrome (CFS)** This name was introduced in 1988 by a group of United States researchers based at the Centers for Disease Control and Prevention and is used increasingly over other designations, particularly in the United States.

**Chronic fatigue immune dysfunction syndrome (CFIDS)** Many people, many patients and advocacy groups in the USA use the term CFIDS (pronounced [See-Fids]), originally an acronym for the above or "Chronic Fatigue & Immune Dysregulation Syndrome". This term was introduced by patients current with the biomedical research in an attempt to reduce the psychiatric stigma attached to "chronic fatigue", as well as the public perception of CFS as a psychiatric syndrome.

**Post-viral [fatigue] syndrome (PVS or PVFS)** This is a related disorder. According to original ME researcher Dr. Melvin Ramsay, "The crucial differentiation between ME and other forms of post-viral fatigue syndrome lies in the striking variability of the symptoms not only in the course of a day but often within the hour. This variability of the intensity of the symptoms is not found in post-viral fatigue states" (Ramsay 1989). However, other researchers and advocates argue that other post-viral syndromes (such as post-polio syndrome) do show similar variability, and point to the striking similarity between post-viral fatigue syndrome and CFS symptoms, noting that many CFS cases are triggered by a viral illness.

**Chronic Epstein-Barr virus (CEBV) or Chronic Mononucleosis**; the term CEBV was introduced by virologists Dr. Stephen Straus and Dr. Jim Jones in the United States. The Epstein-Barr virus, a neurotropic virus that more commonly causes infectious mononucleosis, was thought by Straus and Jones to be the cause of CFS. Subsequent discovery of the closely related human herpesvirus 6 shifted the direction of biomedical studies, although a vastly expanded and substantial body of published research continues to show active viral infection or reinfection of CFS patients by these two viruses. These viruses are also found in healthy controls, lying dormant.

**Low Natural Killer cell disease**; this name is used widely in Japan. It reflects research showing a reduction in the number of natural killer cells in many CFS patients.

**Yuppie Flu**; this was a factually inaccurate nickname for CFS, first published in a November 1990 Newsweek article. It reflects the belief that CFS mainly affects the affluent ("yuppies"), and implies that it is a form of malingering or burnout. CFS, however, affects people of all races, genders, and social standings, and this nickname is inaccurate and considered offensive by patients. It is likely that this article contributed to the damaging public (and even medical) perception of CFS as a psychiatric or even psychosomatic condition.

Uncommonly used terms include **Akureyri Disease**, Iceland disease (in Iceland), **Royal Free disease** (after the location of an outbreak), **raphe nucleus encephalopathy**, and **Tapanui flu** (after the New Zealand town Tapanui where the first doctor in the country to investigate the disease, Dr Peter Snow, lived).