



Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Autumn 2010

Future dates

Afternoon meet – Tuesday 23rd November – 4pm

The Boatman - Millbrook, Guildford, GU1 3XJ

The Boatman is what used to be the Weyside pub. It is now a free house that offers an extensive food menu throughout the day ranging from light bites to pub classics. The Boatman is close to the bottom of Guildford High Street, next to Millbrook open air car park.

Christmas Dinner – Tuesday 14th December – 6.30pm

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

We have booked seats at the Seahorse. If you would like to come please contact Maggie Lilley on Tel: 01483 890620. There are limited seats so we are taking bookings on a first come first served basis.



Booking required !

Morning meet – Wednesday 26th January 2011 – 11am

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.

National ME/CFS observatory

In March 2006, Action for M.E received over £500,000 from the Big Lottery Fund to establish a National ME/CFS Observatory. The grant enables a coherent programme of research into the causes and distribution of M.E.

The Observatory consists of a network of academic institutions with complementary interests in M.E. and CFS. The project is co-ordinated by Dr Derek Pheby, an epidemiologist, former member of the Chief Medical Officer's Working Group on CFS/ME and former trustee of Action for M.E.

The Observatory aims to produce and support the development of social and epidemiological research which responds to the needs of the M.E community.

Further information: www.afme.org.uk/me_cfsObservatory.asp

ME/CFS services directory

The 'ME/CFS services directory' is a lottery funded web-based directory that is provided on the Action for ME website. The directory is a searchable collection of information and contact details of services that may be useful to adults with ME/CFS in England. Some are provided by public bodies, some by charities or support groups, some by private companies - some are free and some will have to be paid for. Further information: www.afme.org.uk/me_cfsDirectoryServices.asp

Norwegian study finds XMRV in 50 of 80 ME/CFS patients tested

October 24, 2010

The following news release was distributed Oct 24, 2010 by the European ME/CFS research & education think tank, ESME (<http://esme-eu.com>). Note that the Lillestrom Health Clinic, which conducted the study, plans to launch a broad international project in November to study human gammaretrovirus in ME/CFS.

XMRV Retrovirus Found in 62% of ME Patients Tested in Lillestrøm, Norway

The Lillestrom Health Clinic has now tested 80 patients and 50 are positive by either culture or serology test – a total of 62%. This is very close to the 67% of positive patient results reported by Mikovits, Lombardi, et al., in Science in Oct. 2009. More information about these results will be given on the 28th of November in Oslo at the XMRV/MLV seminar with Dr. Judy Mikovits.

The tests were done in cooperation with VIPdx labs in the USA.

The Lillestrom Health Clinic is currently cooperating with many international ME experts in order to share knowledge about testing, treatment and research. Dr. Johnsgaard is also cooperating with international experts who specialize in infectious diseases (Borna virus), retrovirology and biotoxic illnesses (Shoemaker), a probable secondary phenomenon in ME.

In November 2010, the clinic will launch a large international research project on Human Gammaretrovirus and ME.

Nutritional and herbal supplements for anxiety

by Shaheen E Lakhan, Karen F Vieira - October 22, 2010

Source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=15681

The following is only the conclusion of an article which can be found at the source directly above.

It appears that nutritional and herbal supplementation is an effective method for treating anxiety and anxiety-related conditions without the risk of serious side effects.

There is the possibility that any positive effects seen could be due to a placebo effect, which may have a significant psychological impact on participants with mental disorders. However, based on this systematic review:

- Strong evidence exists for the use of herbal supplements containing **extracts of passionflower** or **kava** and combinations of the amino acids **L-lysine** and **L-arginine** as treatments for anxiety symptoms and disorders.
- **Magnesium**-containing supplements, and other herbal combinations may hold promise, but more research is needed before these products can be recommended to patients.
- **St. John's wort** monotherapy has insufficient evidence for use as an effective anxiolytic treatment.

Source: Nutrition Journal, Oct 7, 2010;9:42. PMID: 20929532, by Lakhan SE, Vieira KF. Global Neuroscience Initiative Foundation, Los Angeles, California, USA. [Email: slakhan@gnif.org]

Susceptibility of the human retrovirus XMRV to antiretroviral inhibitors

The following article is quite technical, however, it explains that the retrovirus now associated with ME/CFS, namely XMRV, seems to be sensitive to the anti-retroviral drugs: AZT; tenofovir; AZddA; AZddG; and Adefovir.

Source: Retrovirology, Aug 31, 2010 by Robert A Smith, et al.
August 31, 2010

[Note: the full text of this article is available free at
<http://www.retrovirology.com/content/pdf/1742-4690-7-70.pdf>]

Background:

XMRV (xenotropic murine leukemia virus-related virus) is the first known example of an exogenous gammaretrovirus that can infect humans.

A limited number of reports suggest that XMRV is intrinsically resistant to many of the antiretroviral drugs used to treat HIV-1 infection, but is sensitive to a small subset of these inhibitors. In the present study, we used a novel marker transfer assay to directly compare the antiviral drug sensitivities of XMRV and HIV-1 under identical conditions in the same host cell type.

Results:

We extend the findings of previous studies by showing that, in addition to AZT and tenofovir, XMRV and HIV-1 are equally sensitive to:

- AZddA (3'-azido-2',3'-dideoxyadenosine),
- AZddG (3'-azido-2',3'-dideoxyguanosine), and
- Adefovir.

These results indicate that specific 3'-azido or acyclic nucleoside analog inhibitors of HIV-1 reverse transcriptase (RT) also block XMRV infection with comparable efficacy in vitro.

Our data confirm that XMRV is highly resistant to the non-nucleoside RT inhibitors nevirapine and efavirenz and to inhibitors of HIV-1 protease.

In addition, we show that the integrase inhibitors raltegravir and elvitegravir are active against XMRV, with EC₅₀ values in the nanomolar range.

Conclusions:

Our analysis demonstrates that XMRV exhibits a distinct pattern of nucleoside analog susceptibility that correlates with the structure of the pseudosugar moiety and that XMRV is sensitive to a broader range of antiretroviral drugs than has previously been reported.

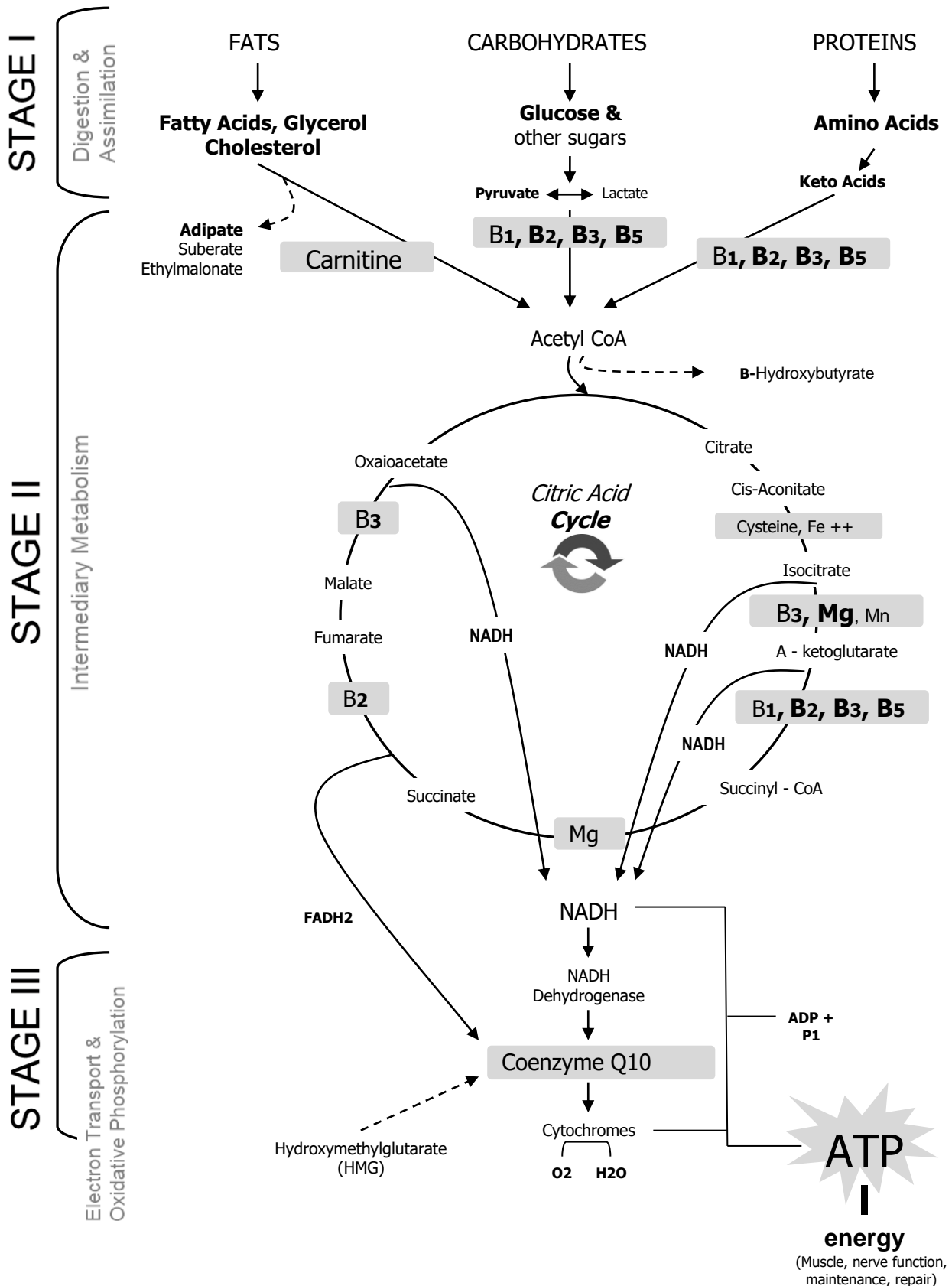
We suggest that the divergent drug sensitivity profiles of XMRV and HIV-1 are partially explained by specific amino acid differences in their respective protease, RT and integrase sequences.

Our data provide a basis for choosing specific antiretroviral drugs for clinical studies in XMRV-infected patients.

Source: Retrovirology, Aug 31, 2010;7:70. doi:10.1186/1742-4690-7-70 Smith RA, Gottlieb GS, Miller AD. Department of Pathology and Department of Medicine, University of Washington, Seattle; Human Biology Division, Fred Hutchinson Cancer Research Center, Seattle, Washington, USA. [Email: smithra@u.washington.edu]

The relevance of energy supplements

The following flow diagram shows what happens to the fats, carbohydrates and proteins that we eat and how they are turned into energy (ATP). Grey boxes show substance's that are used in the process. As such, we can see how supplements of L-carnitine, B-vitamins, Magnesium (Mg), CoQ10 and NADH can help to repair/enhance the process. Related supplement information is included on the following page.



Acetyl-L-carnitine

Acetyl-L-carnitine is an amino acid – a small unit of protein. It occurs naturally in the brain, liver and kidney and plays a role in the normal functioning of the nervous system. The acetyl group that is part of acetyl-L-carnitine contributes to the production of the neurotransmitter acetylcholine, which is required for mental function.

It is also involved in the metabolism of food into energy. Acetyl L-Carnitine is involved in the transfer of long-chain fatty acids, such as triglycerides into mitochondria (a cell's energy powerhouse), where they can be burnt for energy.

Doctors Best Acetyl L-Carnitine - 120 x 500mg Capsules £24.95

From: amazon uk



B-vitamins

AOR's "Advanced B Complex" was designed to take the metabolic, cognitive and overall health benefits of B vitamins to the next level. The product contains Benfotiamine - a lipid-soluble form of B1 that is 5 times more bioavailable than other forms of thiamin, as well as Pantethine, Pyridoxal-5-phosphate (P5P) and Methylcobalamin, bio-active forms of Pantothenic acid, B6 and B12 respectively.

Ingredients:

B1 (Benfotiamine)	100mg	B12 (Methylcobalamin)	1000mcg
B2 (Riboflavin)	7.5mg	Folic Acid (5-Methyltetrahydrofolate)	1000mcg
B3 Niacin (from Inositol Hexanicotinate)	345mg	Biotin	500mcg
B5- Pantothenic Acid (Pantethine)	300mg	Choline (Bitartrate)	600mg
B6 (Pyridoxal-5-phosphate)	100mg	Inositol (from Inositol Hexanicotinate)	384mg



90 Vegi Caps £28.90 www.aoreurope.co.uk

Vitamin B1 is needed to help convert the carbohydrates we eat into glucose. The following B Vitamins are needed at a cellular level to convert glucose into energy - B2, B3, B5, B6 and Biotin. A Vitamin B deficiency in any of these vitamins can lead to decreased energy production, lethargy and fatigue.

B5 is needed for the correct functioning of the adrenal glands and the production of some hormones and nerve regulating substances. B1, B6 and B12 are essential for the regulation and correct functioning of the entire nervous system including brain function. A deficiency in any of the Vitamin B Complex vitamins can lead to feeling stressed, anxious and depressed.

Vitamin B is essential for correct digestion, production of HCl (Hydrochloric acid) and to assist in the breakdown of fats, proteins and carbohydrates. Especially vital for good digestion are B1, B2, B3 and B6. A deficiency in any of these B Vitamins can lead to impaired digestion and deficiency of essential nutrients. In addition, deficiencies can lead to dry, grey skin, dermatitis, wrinkles, acne, rashes, falling hair and weak, splitting nails.

B Vitamins work so closely with one other that a deficiency in any one B Vitamin can lead to poor functioning of any or all of the others even if they are in good supply.

Magnesium

Magnesium Citramate provides magnesium bound to citrate-malate for superior absorption. Both magnesium and malic acid have been found to provide support to individuals with muscle tenderness and fatigue.

Magnesium is present in all cells of the body and is involved in over 300 enzymatic processes, including energy production. Magnesium is essential for maintaining normal bone density, normal cardiac rhythmicity, normal pulmonary function, and normal blood glucose regulation.

90 Vegi Capsules - Thorne Research 150mg Magnesium Citrate-Malate
www.thevitaminservice.com/acatalog/info_HI-M272.html



Magnesium (as a spray for the skin)

Transdermal magnesium therapy represents the fastest and most absorbable way of supplementing this essential mineral. Magnesium is absorbed directly into the skin tissue, entering the cells immediately, bathing and feeding them

BetterYou™ Magnesium Oil uses a super saturated magnesium chloride, solutioned mined in Northern Europe from the ancient Zechstein sea mineral deposits, 250 million years old and one mile below ground. Other sources of magnesium chloride are farmed from open seas and unfortunately contain a growing amount of heavy metals, toxins and pollutants absorbed from over one hundred years of industrialisation.

Zechstein Inside® Magnesium Chloride has remained protected from man-made pollutants and is considered the benchmark for pharmaceutical grade magnesium. Magnesium Oil Original spray is non-greasy and quickly absorbed to give fast acting relief. Each bottle contains up to 800 individual sprays. Suitable for vegetarians, vegans, coeliacs and diabetics.



£9.59 for 100ml from Amazon UK

www.amazon.co.uk/Magnesium-Oil-Original-100ml/dp/B001JJIESG/ref=sr_1_1?ie=UTF8&qid=1288832327&sr=8-1

Feedback left on Amazon UK... "I suffer from ME and was recommended Magnesium Oil to help with all the aches and pains I'd been suffering. After using it for a couple of days 80% of my pains had gone, I've now been using it for a month or so and only occasionally do pains come up and when they do I spray on the oil and they are gone within minutes. I cannot recommend it strongly enough for fellow sufferers of ME/chronic fatigue" By Ms. K. Hill (UK)

NADH

NADH exists in every living organism and is the spark plug in the mitochondria for ATP energy production. A deficiency of NADH will result in an energy deficit at the cellular level, which causes symptoms of fatigue. When the body is deficient in NADH, it is kind of like a car that has run out of gasoline. The more NADH a cell has available, the more energy it can produce.

You may find that the benefits of NADH fade over time, perhaps because either the body or the illness compensates for it. As such it maybe more useful as a a supplement to take on the days preceeding and on the day of a big event.

www.supportme.co.uk/shop.htm

Select "nutritional supplements" then "enada NADH" then how many you want. Perhaps 30 x 5mg is enough to try. NADH is easily destroyed if taken near other food/drink, therefore, take 2 tablets in the morning with water before anything else then nothing to eat/drink for 30 minutes.

CoQ10

Coenzyme Q10 (Co Q10) is a compound found naturally in the mitochondria, the energy-producing center of our cells. Co Q10 is involved in the production of ATP, the main energy source of body cells.

Doctors Best High Absorption CoQ10 - 120 x 100mg Vegicaps £19.46

www.amazon.co.uk/Doctors-Best-High-Absorption-CoQ10/dp/B0019GW38G/ref=sr_1_5?ie=UTF8&qid=1288835300&sr=8-5



Biochemical Balance (CFS blog)

One of our members, Will Marsden, has been creating a blog (personal website) during his ME/CFS illness. As part of trying to understand his illness Will has had to understand a number of biological processes, potential ME/CFS related errors within them and supplements which either ease or help to resolve the errors. Will's blog called "Biochemical Balance" provides technical overviews of some of the biology involved with ME/CFS.



The address for the blog is: <http://bb-cfs.blogspot.com>

The list of topics discussed include:

Antimicrobials, antioxidant, b12, bh4, CBS, coconut oil/monolaurin, cytokine, d-lactate, dysbiosis, energy, excitotoxins, folate, free radical, glutathione, H2S (hydrogen sulphide), heavy metals, immunity, kefir, klebsiella, lithium, magnesium, melatonin, methylation, neurogenesis, neuroprotection, nitric oxide (NO), probiotic, streptococcus

Benefits and Work – guides you can trust

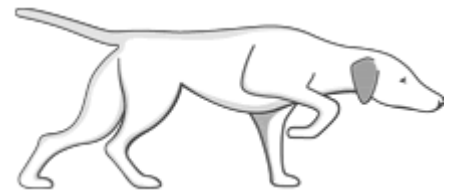
"Benefits and Work" is the name of an website based organisation that provides guides to Disability living allowance (DLA), Employment and support allowance (ESA) and Incapacity benefit (IB).

The site offers information about common pitfalls, expert tips and tactics and guides you through every part of the benefits process.

The website address is: www.benefitsandwork.co.uk

Disability living allowance

Learn how to complete every box in the disability living allowance (DLA) claim pack. Prepare for a medical visit. Represent yourself at a DLA appeal tribunal.



Employment and support allowance

Take our free ESA test. Learn how to complete your questionnaire. Find out what questions you'll be asked at your medical.

Benefits and Work
Guides you can trust

Incapacity benefits

Learn how to give persuasive evidence in your questionnaire. Find out what questions you'll be asked at your medical.

Work

Protect your benefits if you're trying out work. Learn about reasonable adjustments.

Free stuff

Free DLA tests, ESA tests, caselaw and newsletter.

ME patients face UK ban on donating blood

By Michelle Roberts - Health reporter, BBC News - 8 October 2010

Source: www.bbc.co.uk/news/health-11465723

Patients with ME will no longer be able to donate blood in the UK under new safety guidelines.

Officials say the ban, starting on 1 November, is designed to protect the health of people with ME - also known as chronic fatigue syndrome. But the ME Association says the move is motivated by concerns that the illness may be caused by a virus similar to HIV that can be passed on via blood.

Prior to the ban ME patients could give blood provided they were in remission. But the cyclical "relapsing-remitting" nature of this chronic condition means people can become ill again.

NHS Blood and Transplant says the ban is "a precaution to protect the donor's safety by ensuring their condition is not made worse by donating blood". They say the move brings ME blood donation policy into line with other relapsing conditions or neurological conditions of unknown or uncertain origin, such as multiple sclerosis and Parkinson's Disease.

But the ME Association believes there is another reason for the ban - to protect blood recipients from a potentially blood-borne illness. Although they agree with the ban, they say the public should be made aware of all of the reasons for it.

Experts do not know what causes ME. But US scientists recently linked the condition to a retrovirus - known as XMRV - after finding it in the blood of many patients.

Viral infection

The Whittemore Peterson Institute team found XMRV (xenotropic murine leukemia virus-related virus) in 67% of ME patients compared to under 4% of the general population. However since the 2009 discovery, published in the journal Science, other research teams, including experts in the UK, have failed to demonstrate such a link.

A spokeswoman from NHS Blood and Transplant said: "Currently there is no epidemiological evidence of a link between XMRV and CFS in the UK."

Although the evidence is patchy, the ME Association say it is enough to advise caution and recommend a ban on blood donations from ME patients. The American Association of Blood Banks put in place a similar blood ban in June of this year as an interim measure until the true risk of transfusion transmission of XMRV is known. The ME Association's medical advisor, Dr Charles Shepherd, said this was a well-judged approach. "In the current state of uncertainty about a possible viral link a ban is a perfectly sensible measure to take in case it is caused by a retrovirus.

He said the UK ban should not leave a big gap in the blood donor pool. "Although people with ME often want to donate blood, they make up a small number of the many thousands of donations the NHS receives each year."

Seven thousand units of blood a day are needed to meet the demand of NHS Blood and Transplant alone. The ME donor ban applies across all four of the UK's Blood Services.

CFS humour

'The truth about penguins'

by Peter Kemp

I wanted to study the nature of penguins

The Canadian definition of penguins is that they are

flightless
they can swim
largest species up to 1.2m tall
they eat mostly fish
they lay 1 or 2 eggs
they generally live in colonies

the 'CDC' definition of these birds is that they are

flightless
they sometimes eat fish
they lay eggs
they can swim

the 'Oxford' definition is that these birds are:

flightless
they lay eggs

The 'Oxford' definition was chosen for the research as the others were too difficult to apply. 100 subjects who met the research criteria were studies in Sub-Saharan Africa.

The research found that penguins:

live in deserts
cannot swim
are up to 2.4m tall
weigh 200 pounds
capable of speeds up to 40mph on land
are mostly vegetarian

Conclusion

The research has discovered the truth about penguins. Those funny black and white birds waddling about the ice and swimming in the sea are making fools of everyone. They are not real penguins and should be excluded from further research into penguins.

Source: <http://niceguidelines.blogspot.com/2009/12/professor-simon-wessely-and-his-cbt.html>



ME/CFS Worldwide Patient Alliance

We are a group of ME/CFS patient advocates who think now is the time for a change. We hope to create this change through an effective, cutting-edge advertisement campaign, specifically to address what needs to be done to improve the quality of life of individuals with CFS, also known as Myalgic Encephalomyelitis (ME). This will be the patients' voice. It will be our message.



Through this multi-organization campaign, we plan to bring attention to the following needed changes to improve patient quality of life by:

- increasing knowledgeable medical care for patients
- increasing biomedical research funding
- stopping the misinformation
- increasing cooperation between researchers
- making the US Department of Health and Human Services implement the Chronic Fatigue Syndrome Advisory Committee Recommendations
- making US Congress conduct Congressional hearings
- changing the name of our illness to one that reflects the severity of our condition

Ads will be strategically placed in national newspapers, in community newspapers, blogs, and websites to call for changes to improve the quality of life for these patients.

Website: <http://mcwpa.org>

Is it a cold or flu ?

Once again, the season for colds and flu is upon us. There are more than 200 different viruses that can cause a cold, and flu viruses are continually changing, at some point one of them may catch up to you.

If you do get sick, how do you tell if you have a cold or the flu? I often hear people describe any winter illness as the flu, when usually what they have is a bad cold. The table below, from the National Institute of Allergy and Infectious Diseases, compares the two illnesses by symptoms and their severity:



Symptoms	Cold	Flu
Fever	Rare	Usual; high (100°F to 102°F; occasionally higher, especially in young children); lasts 3-4 days
Headache	Rare	Common
General Aches, Pains	Slight	Usual; often severe
Fatigue, Weakness	Sometimes	Usual; can last up to 2 to 3 weeks
Extreme Exhaustion	Never	Usual; at the beginning of the illness
Stuffy Nose	Common	Sometimes
Sneezing	Usual	Sometimes

While low doses of vitamin C may not help us fight colds, higher doses (1,000mg three times a day) can be very effective in supporting the body's ability to fend off and reduce the symptoms of colds. Vitamin D3 reduces risk of respiratory tract infections (e.g. 1000IU or higher daily).

Guaifenesin is a powerful expectorant. It works by drawing water into the bronchi - the air passages branching into our lungs. The released water thins the mucus and lubricates the airway, making it easier to expel the mucus by coughing. It is also considered helpful for reducing nasal congestion, which may in turn relieve sinus pressure and headache.

Book review - The guide to living with severe ME

Health writer Cathy Stillman-Lowe reads through a new book on living as well as possible with severe ME, by Emily Collingridge

Published by the Association of Young People with ME, this new book offers help for those of all ages who are predominantly bedridden, and includes information for both the loved ones and the professionals providing care for this group of patients. At 140 A4 pages packed with detailed and comprehensive guidance, it is neither a short nor a light read, but clear signposting, and key points provided at the end of each chapter, make it easy to dip into to, if searching for advice on a particular topic.

The topics covered range from the very practical – such as keeping comfortable in bed, personal care, mobility and communication; to medical matters, including managing symptoms, and coping in hospital; and emotional aspects, for example getting professional help with depression or anxiety, or the issues affecting carers, siblings and friends. Of great potential value to the severely affected is a chapter on activity management, tailored to their particular needs. The book explains how this is subtly different from the more familiar concepts of pacing and graded exercise, and gives tips on rest, 'switching', and what to do if you experience setbacks or reach a plateau. A wealth of useful contacts for further information and support is provided in an appendix. The book also boasts an 'online home' at <http://www.severeme.info/>, which provides links to a dedicated Facebook group, and to the publishers, AYME. A supplement which offers guidance on completing a Disability Living Allowance claim form is supplied separately at <http://www.ayme.org.uk/article.php?sid=21&id=300>, and the contents pages can also be downloaded as a pdf for those wishing to see in detail what the book covers.

Unflinchingly honest and warmly compassionate, this guide hides none of the reality of severe ME, yet still contrives to offer hope to its readers. The author offers advice that is detailed, positive and practical. Painstakingly researched with both patients and a wide range of professionals, the book provides a much needed guiding light in a sombre world of severe illness and disability. Its quality and breadth of appeal is indicated by the endorsement of its contents by reviewers as diverse as Simon Lawrence of the 25% ME Group who describes the book as 'an invaluable resource' and Professor Tony Pinching, who rates it as 'immensely useful to patients and professionals alike'. The production of this reference book whilst severely affected by ME herself is an extraordinary achievement by Emily Collingridge.

'Severe ME/CFS: A Guide to Living' costs £5.99 including p&p, or £3 for AYME members registered as Severely Affected. To contact the publishers, AYME - Telephone: 08451 23 23 89 - Post: AYME, 10 Vermont Place, Tongwell, Milton Keynes, MK15 8JA
Email: info@ayme.org.uk.