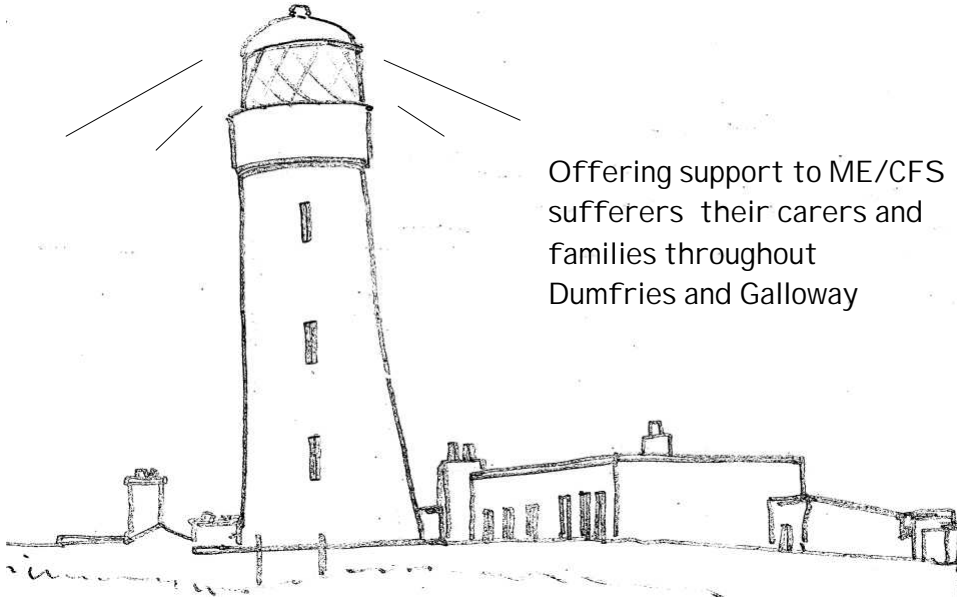


Dumfries and Galloway M.E. Network

Registered Charity SC30641

Issue No. 44

Winter 2008



Offering support to ME/CFS
sufferers their carers and
families throughout
Dumfries and Galloway

Visit our Website - www.dgme.co.uk

Afternoon Meeting

Friday April 4th

See inside for details

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Dear Member

We hope that you enjoy the winter newsletter, sorry that it is late again, this was due to an escalation of problems and events that held everything up.

I would like to take this opportunity to welcome you to come along to the meeting advertised on page three, it should be very interesting, we would love to meet more of our members, we realise for some the travelling distance is too far—D&G covers a large area and localised meetings are hard to arrange

The latest news on the X-Party Group page 18 is because so many people were unhappy with the first draft and the time scale for a completed document, a decision has been made to put it on hold for a new draft to be formulated, this could take six months or even longer, Our Network will still be involved through the Stakeholder Group.

We have had some lovely weather of late, and spring is just around the corner, I'm sure you all know the saying - Ne'er cast a clout till May be out. Until next time,

Take care and Keep warm

Norma



The real Bambi and Thumper!

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Welcome To An Afternoon At Lochthorn Library. Dumfries Friday 4th April 2.pm— 4.pm.

The Speaker will be Sylvia McCracken from "Arthritis Care"
Sylvia will be giving us a taster about the
courses that are run by Arthritis Care they are suitable for other chronic illnesses
and therefore could be beneficial to
ME/CFS/FM sufferers. The courses are for one afternoon a week, some course's
are over a six week period, while others are only over two weeks.
Dr Purdie, our Medical Adviser, is also hoping to attend.
Our meetings are quite informal and friendly. Refreshments are available and there
is no charge, but if anyone would like to give a donation to MERUK a collection box
will be available for donations. This is the day before a Garden Wise get-together
but unfortunately it was the only date available. We hope as many of you as possible
will be able to come and join us for an interesting and informative meeting.

Challenging Your Condition

This is one of the six week courses available and the next one takes place at
Macmillan Hall, Dashwood Sq, Newton Stewart. Monday 31st March/08
Until Monday 5thMay/08 Time 1.30 to 4pm

It is advised that if you want to get the full benefit of the course you really need to
attend all six sessions. There are still a few places left if you would like to register
or if you want more information Phone Alex Frame on 0141 954 7776.

What is covered during the six week course.

Week 1

Introduction—I identifying common problems
Course overview and responsibilities
Differences between acute & long-term conditions
Using your mind to manage symptoms
Better Breathing
Introduction to action plans

Week 2

Feedback/problem solving sessions
Dealing with difficult emotions
Introduction to physical activity & exercise
Making an action plan

Week 3

Feedback/problem solving session
Distraction
Muscle relaxation
Pain & Fatigue management
How to monitor your exercise:How much is enough?
Making an action plan

Week 4

Feedback/problem solving sessions
Healthy Eating
Future plans for health care
Communication Skills
Problem-solving
Making an Action Plan

Week 5

Feedback/problem solving sessions
Medication usage
Depression Management
Positive thinking
Guided Imagery
Making an Action Plan

Week 6

Feedback/problem solving sessions
Making informed treatment decisions
Working with your health care professional
Looking back
Looking forward

Allergies Linked to IBS

Adults with allergy symptoms report a high incidence of Irritable Bowel Syndrome (IBS), suggesting a link between atopic disorders and IBS according to a study published this month in *Annals of Allergy, Asthma & Immunology*, the scientific journal of the American College of Allergy, Asthma and Immunology (ACAAI).

In a study of 125 adults, Mary C. Tobin, M.D, Department of Immunology/Microbiology at Rush University Medical Center, Chicago, and colleagues found the likelihood of IBS was significantly higher in patients with seasonal allergic rhinitis (2.67 times), patients with allergic eczema (3.85 times) and patients with depression (2.56 times)

Irritable Bowel Syndrome, affecting 15 percent of the general population, is a cluster of symptoms including abdominal pain for 12 weeks within the past year, change in stool consistency or frequency, and relief of abdominal pain with defecation. Various findings suggest indirectly that allergen exposure may lead to IBS symptoms in some patients, but the frequency has not been studied.

"The reported presence of allergic dermatitis was highly correlated to the presence of IBS in our population," investigators noted. "In atopic disease, allergic dermatitis is the first step of the 'atopic march.' In early childhood, AE (allergic eczema) is frequently associated with gastrointestinal dysfunction and food allergy. A clinical history of AE may be a useful marker for patients with gut hypersensitivity and atopic IBS."

Asthma and Irritable Bowel Syndrome was reported by 12 of 41 patients (29 percent), which is similar to findings in a previous report. Authors propose that "this subgroup of IBS (atopic IBS) be considered separately from patients with IBS without atopic symptoms, because they may have distinct pathophysiologic features and may benefit from specific therapeutic interventions."

Is irritable bowel syndrome due to a food intolerance?

It is very worthwhile to investigate food intolerance as a cause of IBS. Indeed research in the United Kingdom further supports this:

Studies at Addenbrooke's Hospital in Cambridge found that of 182 IBS patients dietary changes were able to completely relieve symptoms in 122 cases. There is only one failsafe and accurate way to identify food intolerance and that's by doing an Elimination Diet.

Estimates for IBS in the UK vary from 20% to 33% of the population at any one time. That is about one in every four people. A common factor among people suffering from IBS is stress. It has been repeatedly and consistently linked with major life events like loss of a job, birth of a child, death in the family or relationship breakdown.

Food intolerance also causes stress to the digestive system, which may explain IBS in some cases. If we continue to consume foods that our bodies perceive to be invaders, then that is simply another kind of stress. IBS is consistently associated with food intolerance, an inability to properly digest one of Dairy, Yeast, Gluten or Fructose. Remember Food Intolerance is extremely common, known to affect up to 75% of the world's population.

IN THE NEWS

Feels Like Rain

Some people with disorders like arthritis and fibromyalgia believe their symptoms are impacted by the weather

Recently a group of researchers from the Instituto Portugues de Reumatologia evaluated the perceived influence of weather changes on pain and symptoms of a group of 955 rheumatic patients.



Fibromyalgia patients seemed to be strongly influenced by weather changes, the researchers wrote, and 70 percent of study participants perceived changes in their pain levels and symptom activity as the weather changes.

Do you think your body is a Barometer"? Does the weather affect your FM/ME/CFS? Let us know what you think ED

Botox

You might well be wondering what has Botox got to do with ME and I expect that sufferers mainly women like myself feel too ill most of the time to be worrying about wrinkles! Not to mention the cost, for people on benefits luxuries are usually a no-no. But another reason to think again for anyone planning this treatment was the reference to neurological disorders in the following article found on the BBC news web site.

The lack of regulation for cosmetic treatments such as Botox is to be raised at the Scottish Parliament.

The Conservative spokeswoman for health and wellbeing, Mary Scanlon, said she wanted the government to look at the increased use of such treatments.

Her move comes after a BBC Scotland investigation found one in 10 clinics, hairdressers and beauty salons were not sticking to standards for using Botox.

About 40 premises were contacted as part of the investigation.

Ms Scanlon said many people did not realise they were injecting toxins when being given Botox.

Speaking on BBC Radio's Good Morning Scotland programme, she said: "It is not licensed for use as a cosmetic aid, it is in fact licensed for the release of muscle spasms and the management of sweating of the armpits.

'Cause for concern'

"There are causes for concern because it can lead to double vision, facial paralysis and there are worries that it shouldn't be administered to patients with neurological disorders."

She said it was time for the Scottish Government to have a new look at its regulation.

So-called 'friendly' bacteria may be dangerous, according to new research – so which should you be taking?

By PETA BEE Daily Mail 29th Jan 2008

This article covers a different perspective on Probiotics and Bacteria
Printed in the Autumn Newsletter.



Yakult: The drink contains ingredients which ensures the 'friendly' bacteria have good survival rates. With their promise to rid the body of the "bad bacteria" that make us ill, it's no wonder so many of us are buying probiotic dietary supplements.

Two million Britons now regularly consume these "friendly" bacteria in the form of drinks, yoghurts, powders and capsules. "Friendly bacteria" sound so harmless.

So what then are we to make of the story last week that patients with pancreatic disease had died as a result of being given them?

Doctors at the University Medical Centre in Utrecht, Holland, reported that 24 out of 296 patients died during a study to find out whether friendly bacteria - known as probiotics - affected inflammation of the pancreas.

The researchers said their results were proof that "extremely ill" people should avoid probiotics, and the Dutch Food and Consumer Product Safety Authority has ruled that supplements should not be given to patients in intensive care, those with organ failure or anyone being fed through a drip. So should we be concerned about the new findings? In fact, when it comes to seriously ill patients, many UK hospitals already follow the approach being adopted by the Dutch, says Catherine Collins, chief dietician at St George's Hospital in London. In unhealthy people with weakened immunity the so-called friendly bacteria, such as lactobacillus casei or bifidobacteria, which make up probiotics, are treated as hostile invaders. "In some cases they can induce a potentially fatal condition called lactobacillus septicaemia," says Collins. "We've treated two cases recently at St George's." A lot of hospitals don't embrace probiotics because the living bugs they contain have the potential to cause infection in vulnerable people.

But what does this mean for the rest of us? Probiotic products aren't dangerous for healthy people, says Claire Williamson, a nutrition scientist with the British Nutrition Foundation, but adds that manufacturers are often guilty of exaggerating their benefits. Probiotics are a relatively recent "invention". — — It's now generally accepted that the human gut contains different strains of bacteria, some of which are beneficial, some that help with food digestion and some that are disease-causing.

But do supplements help maintain the "healthy" balance of these bacteria, as proponents of probiotics suggest? Earlier this month, Professor Jeremy Nicholson, chair in biological chemistry at Imperial College London, revealed that lactobacillus probiotics seem to enhance digestion and may even assist weight loss by preventing the body from absorbing fat in food. But Nicholson and his team were not sure how or why they work and say that, because the studies involved mice not humans, more investigations need to be carried out.

"They can have an effect but we are still trying to understand what the changes might mean in terms of overall health," he says.

"We have established that introducing friendly bacteria can change the dynamics of the population of microbes in the gut and could reduce the amount of fat digested by the body, but more work is needed in this area."

Claire Williamson says: "There is some evidence that probiotics can help to stabilise gut flora that is disrupted when people take antibiotics, and also that the supplements can reduce symptoms of IBS.

"But as yet the findings are inconclusive and should be treated with some caution." Critics doubt whether probiotic bacteria survive transit through the gut and suggest they are likely to be killed by acid in the stomach.

They also argue that a pot of probiotic yoghurt containing 1-5 million bacteria is unlikely to have any impact on the 100 trillion bacteria in gut microflora.

Indeed when Glenn Gibson, professor of microbiology at the University of Reading, analysed a range of probiotics on sale in the UK in 2006, he found up to half of them were useless and some contained types of bacteria that rendered them potentially harmful.

"Around half the products don't match up to what their label says and have either the wrong bacteria or the wrong numbers," he said.

However, better-known brands such as Actimel and Yakult were found by Gibson to contain at least ten million friendly bacteria from the lactobacillus or bifidobacteria families, which means they might be effective in aiding digestion.

Another pointer for the types of products to look for came from an earlier study Gibson conducted for the Food Standards Agency.

This showed that products containing high levels (ten million to several billion) of bifidobacterium and enterococcus faecium had the best survival rates in the upper intestine and that lactobacillus bacteria survived for up to five days in the lower intestine. Drinks containing lactose or oligosaccharides (such as Yakult) or supplements that were enteric-coated - so don't dissolve until they reach the intestine (Multibionta) - have the best survival rates.

However, Gibson's tests showed that even if they did survive, probiotics did not necessarily lead to a beneficial increase in friendly gut flora. In other words, to some people they may be useless.

Furthermore, many nutritionists, such as Sue Baic, a spokeswoman for the British Dietetic Association, believe a better way to promote natural good gut bacteria is to consume prebiotics - substances that support existing gut bacteria.

Found in human breast milk, prebiotics contain oligosaccharides, a type of carbohydrate that only our guts can feed upon and which are necessary for friendly bacteria to multiply and flourish.

"There are dietary sources such as onions, garlic, chicory and banana," she says.

"But because we don't eat enough of these, a supplement such as fructooligosaccharide may help friendly bacteria to grow in the gut."

BITS 'N' PIECES

Dr Mark Porter is a medical doctor who appears on television and radio to advise on medical problems. He also has a weekly programme on radio 4 called Case Notes, where individual medical conditions are discussed for the whole programme and he is health consultant for Jeremy Vine's programme on Radio 2. He has columns in the Evening Standard, Sainsbury's Magazine and Closer Magazine.



Understandably not everyone is happy with his comments and recent advice, for instance Taken from Sainsbury's Magazine page 31 of the February 2008 issue. He writes -:

'Put Fatigue to Bed'

Going to bed early, and or lying in is the last thing you should do if you're battling chronic fatigue after an illness such as glandular fever. Restricting sleep to no more than eight hours a night increases the quality of sleep, and is now one of the key approaches being used to manage people with chronic fatigue syndrome / ME.

Dangerous stuff! If anyone knows how to contact him—please do—we would love to know where his source of information came from.

And although the NICE Guidelines are not for Scotland when he made comments in The Evening Standard that CBT inclusion should be welcomed Dr Charles Shepherd wrote -

Dr Mark Porter has missed the point about why ME charities are opposing the NICE (National Institute for Health and Clinical Excellence) guideline.

Of course, we welcome the conclusion from NICE that ME is a serious and disabling illness - as this is consistent with the World Health Organisation classification of it being a neurological disorder.

And nobody would dispute the fact that psychological treatments such as cognitive behaviour therapy (CBT) can sometimes help people cope with the emotional distress that may accompany any serious physical illness, including ME.

But in the case of ME, NICE are recommending that CBT, or graded exercise treatment, should be the only forms of specific treatment for everyone in the mild to moderate category - even though patient evidence submitted to the Chief Medical Officer's report found that these expensive courses of treatments are often ineffective (67% in the case of CBT) and may even be harmful (50% in the case of graded exercise).

If everyone with cancer was being offered CBT as the only basic treatment option available they would be horrified. Exactly the same logic applies to people with ME.

Incidentally, the British Psychological Society, who represent psychologists using CBT, have also criticised the inflexibility of the NICE guideline.

Dr Charles Shepherd Honorary Medical Adviser, ME Association.

Perhaps more people should put Dr Porter right on ME issues. - Ed




Gift Day

Once again a huge thank you to our members for donating the fantastic amount of £807 00 on our annual Gift Day. As you will be aware we are all too ill to arrange fundraising events, so we do appreciate your generosity in helping The Network to be able to carry on with the work we do with your direct giving.
The Committee.

Welcome to Zoe Little

Originally born and bred in Moffat. I went to college in Newcastle to study fashion and decided to stay there for a few years before getting itchy feet and moving to Glasgow to enjoy city life for a year. I am currently living in Dumfries and working in Andersons Ltd as an Administrative Assistant. I am delighted to have been asked to become the Treasurer for the D&G M.E Network.



Donating Blood. 15 January 2008

From time to time The ME Association is asked if people with ME/CFS can donate their blood. The current advice from the UK National Blood Service (NBS), which has been re-checked today, is that: 'You may give blood when you feel you are completely recovered and have no further symptoms and no treatment is required'

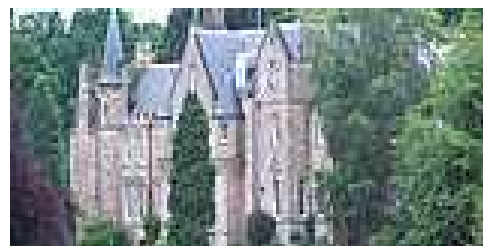
This NBS advice specifically applies to people with PVFS. An NBS adviser has confirmed that this advice also applies to people with ME and CFS.

The NBS can be contacted on: 0845 7711 711 (UK). Website: www.blood.co.uk
We would be interested to hear from ME/CFS contacts overseas regarding the blood donation situation in other countries. We will summarise this information in a further internet posting.

Dr Charles Shepherd.

Hon Medical Adviser, ME Association

At the moment Carberry Tower is undergoing refurbishment. This means that the next 'Caring Break' for people with ME is not until September 2008.



The New Horizons 2008 conference

On ME/CFS biomedical research will take place on Tuesday 6th May 2008 at the Wellcome Trust Genome Campus, Hinxton, Cambridge, UK. which can cater for up to 300 delegates and is within easy reach of Cambridge, the M11 and London Stansted Airport. Hosted and sponsored jointly by ME Research UK and the Irish ME Trust.

Building on the success of last year's New Horizons conference held at Edinburgh, we hope that the day will be of interest to a wide range of professionals, patients and observers. As ME/CFS biomedical research is very varied, spanning many scientific disciplines and involving a wide range of healthcare professionals, this research conference will provide the opportunity for researchers and healthcare professionals within ME/CFS to present their latest work, share ideas and identify key challenges for the future. The preliminary outline for the day includes presentations by:

- Dr Vance Spence (Chairman, ME Research UK, and Senior Research Fellow, University of Dundee) — Overview of ME/CFS: the Research Challenge Prof.
- Nancy Klimas (University of Miami School of Medicine, Florida, USA) — Immunologic and Clinical Aspects
- Dr Stephen Graves (Australian Rickettsial Reference Laboratory, NSW, Australia) — Q fever, Rickettsia honei and ME/CFS
- Dr Neil Abbot (Research Fellow, Institute of Clinical Research, University of Dundee) — Systematic Review of Biomedical Studies in ME/CFS
- Annette Whittemore (President, Whittemore Peterson Institute for Neuro-Immune Disease, Center for Molecular Medicine, University of Nevada School of Medicine) — Biomedical research in Nevada
- Dr Gavin Spickett (Consultant Clinical Immunologist and Clinical Champion for the Northern Clinical Network Co-ordinating Centre (CFS/ME) Service, Newcastle Primary Care Trust, Newcastle upon Tyne) — The role of the CFS/ME Clinic
- Dr Julia Newton (Senior Lecturer, Institute of Cellular Medicine, Newcastle University) — Autonomic investigations
- Dr Jonathan Kerr (Department of Cellular and Molecular Medicine, St George's University of London) — Molecular studies
- Dr Byron Hyde (Nightingale Research Foundation, Ottawa, Canada) — Results from a longitudinal database
- Dr Faisal Khan (Vascular Diseases Research Unit, University Department of Medicine, Dundee) — Vascular and Inflammatory

Registration will be from 8.30 am, with a 9.00 am start and an expected finish of 5.00 pm. The registration fee is £145 for professionals, and £60 for patients, ME support group representatives and students. Included in the registration fee are a finger buffet lunch, and morning and afternoon coffee/tea breaks, served on-site.

Vitamin D Inadequacy May Exacerbate

Chronic Pain

Approximately one in four patients who suffer from chronic pain also have inadequate blood levels of vitamin D, possibly contributing to their ongoing pain, according to a new study at the American Society of Anesthesiologists 2007 Annual Meeting in San Francisco. Patients lacking sufficient vitamin D also required higher doses of morphine for a longer period of time.



Researchers recorded the serum vitamin D levels of 267 adults undergoing outpatient treatment for chronic pain, as well as their pain medication (morphine) dose and duration of use, and physical and general health functioning.

Of the patients tested, 26 percent had vitamin D inadequacy. Among these patients, the morphine dose was nearly twice that of the group with adequate vitamin D levels. In addition, the vitamin D inadequacy group used morphine for an average of 71.1 months versus 43.8 months. The vitamin D deficient group also reported lower levels of physical functioning and had a poorer view of their overall health.

It has long been known that inadequate levels of vitamin D can cause pain and muscle weakness, according to the study author, W. Michael Hooten, M.D., medical director, and anesthesiologist at Mayo Comprehensive Pain Rehabilitation Center, Rochester, Minnesota. Previous studies also have suggested that pain-related symptoms of vitamin D inadequacy respond poorly to pain medications.

However, "this is the first time that we have established the prevalence of vitamin D inadequacy among a diverse group of chronic pain patients," Dr. Hooten said.

"The implications are that in chronic pain patients, vitamin D inadequacy is not the principal cause of pain and muscle weakness, however, it could be a contributing but unrecognized factor," Dr. Hooten said.

Vitamin D inadequacy can be "easily and inexpensively" treated "with essentially no side effects" using a prescription supplement, once or twice a week for four to six weeks, Dr. Hooten said. Further study is needed to determine whether treating inadequate vitamin D levels will result in improvements to the overall general health for patients with chronic pain.

Founded in 1905, the American Society of Anesthesiologists is an educational, research and scientific association with 41,000 members organized to raise and maintain the standards of the medical practice of anesthesiology and improve the care of the patient. Visit our Web site at <http://www.asahq.org>.

A friend of mine who suffers from MS says anyone that lives north of Birmingham should take extra vitamin D. She went on to say you can get it on prescription and she definitely feels a benefit for taking it. Always check with your GP first ——— Norma

Dentistry

Visiting the Dentist can be daunting for most but if you suffer from ME/CFS/FM there are other problems to encounter (presuming you have a dentist these days!) A patient with ME/ CFS may have oral manifestations, such as Temporomandibular disorders, TMD, TMJ Syndrome. Joint Dysfunction. The temporomandibular joint (TMJ) connects your jaw to the side of your head. When it works well, it enables you to talk, chew and yawn. For people with TMJ dysfunction, problems with the joint and muscles around it may cause -:



- Pain that travels through the face, jaw or neck
- Stiff jaw muscles
- Limited movement or locking of the jaw
- Painful clicking or popping in the jaw
- A change in the way the upper and lower teeth fit together

Jaw pain may go away with little or no treatment. Treatment may include simple things you can do yourself, such as eating soft foods or applying ice packs. It may also include pain medicines or devices to insert in your mouth. Another manifestation is Sjögren's syndrome, (Dry mouth, eyes) and fibromyalgia (myofascial pain). Furthermore, many of the medications prescribed to manage ME/CFS can induce a variety of oral side effects, most commonly xerostomia. (Dry mouth)

It is important to have routine check-ups and dental treatment when necessary, including prophylaxis, dental prophylaxis is removing plaque and cleaning the teeth to prevent cavities and gum disease. Incidentally the word "prophylaxis" is from the Greek and means "an advance guard". Some ME sufferers have problems with injections containing Adrenalin. If this affects you, ask your dentist for an injection without adrenalin.

Fibromyalgia

Bruxism frequently affects people with fibromyalgia. This disorder causes muscle pain in the face, neck, shoulders, and back, and often leads to grinding of the teeth. 75% of people with fibromyalgia also have TMJD.

Nocturnal bruxism occurs when you are sleeping. For some reason, sufferers begin to clench the muscles in their face causing their teeth to grind together. Many are unaware of this as they are sleeping, but in the morning they can be left feeling achy and sore in the jaw area.

Bruxism can lead to a variety of dental problems, including loosened and broken teeth.

Treatment generally involves the use of dental orthotics. These are often used to prevent symptoms of severe bruxism. Dental night guards made from metal and acrylic are inserted into the mouth each night. These guards provide a flat surface for your teeth to clench onto, preventing further tooth or jaw damage. Because they cover the teeth, night guards also help to eliminate tooth grinding.

RESEARCH CHALLENGES IN ME/CFS

DR NEIL ABBOT, RESEARCH & OPERATIONS DIRECTOR, ME RESEARCH UK



INTRODUCTION For Socrates, uncertainty was better than certainty because it presented challenges which, when overcome, resulted in the discovery of the real facts of the world. From this lofty viewpoint, then, ME Research UK should be proud to be working in the field of ME/CFS. Aside from the usual challenges of conventional biomedical science (isolating the cause of the illness, testing therapies and developing treatment programs), there are particular challenges specific to ME which impact on “making a breakthrough”. What are these additional challenges, and how might they be overcome to the benefit of patients, estimated by the 2007 NICE guideline to number over 193,000 in the UK alone (250,000 people with ME according to some charities)?

FUNDING CHALLENGE Money is the platform which supports all biomedical research. But there is a problem: medical research is expensive, one medium sized clinical trial can cost £300,000 and can possibly have an inconclusive result. So big money will be needed to unravel the causes and find cures for ME/CFS. The larger national agencies (called Class 1 funders), such as the Medical Research Council (MRC) and the NHS Research and Development, allocate funds to established research groups with a track record of success in a certain area, on the basis of a reasonable scientific hypothesis. It is very difficult, however, for any researchers in any field to obtain funding from these central sources.

The MRC funds only 4 out of every 20 applications, sometimes only after substantial revision and in any case the money available (some £1.3 billion in the current year, for all types of research across all illnesses) does not go far given the expense of the investigations and many demands made. Even if the biomedical investigation of ME/CFS got its fair share of Class 1 funding, something that many of us are still pressing for, that share would fund only a small part of the biomedical activity that is necessary.

In fact, a significant proportion of research funding for many, if not all, illnesses comes from charitable sources — the Association of Medical Research Charities estimates that some £791 million was spent on projects in 2006/7 by its members. The beauty of these sources is that unlike government sources they are illness-specific, since donors can give to the cause of their choice: taking cancer as an example, the annual income of Cancer Research UK to 31st March 2007 was £468 million and it is only one of a large number of cancer charities. Much of this income comes directly or indirectly from public donations.

We have to do the same for ME/CFS. As most patients are too ill to fundraise themselves, our strategy has to be to raise awareness of the need for biomedical research into the illness, ensure that our organisations are worthy of the trust and support of patients, carers and fundraisers, and get and keep the research community on side in the struggle.

DIAGNOSTIC CHALLENGE CFS is not a ‘clean’ diagnosis. In 2007, there are at least three different definitions of CFS in use, all non-validated and all based on vague, non-specific symptoms shared with other common illnesses. While it is likely that they overlap, they do not necessarily contain scientifically comparable groups of patients, a fact which complicates the comparison of studies and raises questions about how representative are the findings of any particular study. In a biomedical world which prizes homogeneous groups of patients — those with a confirmed diagnosis, sharing similar signs and symptoms and fulfilling strict criteria — it is a real complication.

What can be done about this? We could return to diagnosing ‘classic’ myalgic encephalomyelitis

One strategy which has a lot of support is to subgroup patients on the basis of symptom clusters. The Canadian definition of 2003 could be the basis for such an attempt, or on the severity of existing symptoms (which might result in the identification of 'classic' ME patients at one end of the spectrum, as suggested in a scientific paper in 2003 (1).

Whatever the eventual resolution, this central problem tends to increase the costs of research studies, because ideally volunteers need to be screened and categorised by medical examination. Interestingly, however, biomedical anomalies can indeed be found in patients diagnosed with ME/CFS. There are many reports out there which show this; e.g., the report in September 2007 (2) describing the discovery of enterovirus VP1 protein in 135/165 (82%) of stomach biopsy samples of CFS patients compared with only 7/34 (20%) of control samples; or the paper in 2004 which identified, after clinical examination, muscle weakness in the lower limbs, and absent or abnormal reflexes in ME/CFS patients (3). And it may be that careful screening for ME/CFS, with proper exclusion of those with differential diagnoses, is one of the most useful things that can be done.

THE ELEPHANT IN THE ROOM The 'elephant in the room' — ever-present but rarely alluded to in the media or the mainstream scientific literature, concerns the overarching influence of the psychosocial model of the illness, which emphasises "beliefs, coping styles, and behaviours" (summarised in the Chief Medical Officer's report of 2002). It colours the perception of the illness across the board, from official reports such as the 2007 NICE Guideline, to the policy of government agencies such as the Department of Work and Pensions and NHS Plus. But it also impacts on research. In most illnesses, research on psychosocial aspects is an adjunct to the contemporaneous biomedical research that spearheads the drive towards a cure. Yet, in ME/CFS, psychosocial investigation seems to have hoovered up attention and funding at the expense of hard-core biomedical investigation.

Take the Medical Research Council for example: the vast bulk of its £3 million ME/CFS grant-spend since 2002 has gone towards research into psychological management strategies, while around 30 other applications, some from established biomedical research groups with a track record in the field, have been rejected. Facts we only know because some stalwart patients have requested the information under the Freedom of Information Act. Moving basic scientific and clinical research centre stage, into the spotlight presently occupied by psychosocial models in the minds of opinion formers and healthcare professionals, is one of the greatest challenges.

ATTRACTING RESEARCHERS ME/CFS biomedical research is not 'sexy' in scientific terms — in this respect it resembles leprosy, a field I worked in a decade ago. Because its profile is low and coloured by the emphasis on psychosocial aspects of the illness, and characterised by disparaging labels ("yuppie flu", "all in the mind"), and because researchers looking in would see little chance of high-level funding, encouraging established researchers into the field — and attracting fresh young investigators — is one of the biggest problems we face.

However, by advertising inside the NHS, by encouraging applications from our website and hosting conferences (as well as a little personal persuasion), we are convinced that interest is slowly increasing. ME Research UK now provides funding to the Universities of Newcastle, Dundee, Strathclyde, Brussels, London (St George's and Hammersmith), Glasgow and Calgary.

TARGETING SCARCE RESOURCES Research charities such as Cancer Research UK which raise millions of pounds per annum have the luxury of providing core funding for dedicated research units year-on-year, offering specific researcher awards, and commissioning their own research. As yet, this has not been possible in ME/CFS, so ME Research UK's short-term strategy has been to provide essentially pilot funding to 'pump prime' work of potential importance. The resulting publications help to build critical mass in the scientific literature and the data obtained can form the basis of researchers' subsequent applications for Class 1 funding. The challenge here is to make the best use

NEED FOR CONSISTENCY There is also a need for consistent directed work over a broad front. Funding a smallish pilot study is one thing, but real breakthroughs come at the end of a programme of painstaking work by a specialist group of researchers. One of the few examples in ME/CFS in the world is the work at the Vascular Diseases Research Unit, University of Dundee, which has received several grants from ME Research UK since 2001. In a step-by-step progression involving both adults and young people with the illness, the group has uncovered:

- unusual sensitivity of blood flow responses to acetylcholine (a neurotransmitter),
- increased levels of isoprostanes (a gold standard marker of oxidative stress in the bloodstream),
- an unexpected increase in dying (apoptotic) white blood cells, consistent with an activated inflammatory process or persistent infection, and
- increased cardiovascular risk factors with arterial stiffness in patients.

Such a progression — whether towards positive findings or away from negative ones — is the norm for scientific investigation. The burning need in this illness is for there to be many groups undertaking programmes of research across a range of basic and clinical sciences fields so that a ‘critical mass’ of investigators can produce a ‘critical mass’ of biomedical data.

CONCLUSIONS There cannot be many other illnesses in which so many unusual challenges stand in the way of ‘making the breakthrough’. The ideal scenario would be for central (e.g., MRC and NHS R and D) funding of biomedical research to be provided through a form of ring-fencing, making it much easier to entice good, established biomedical researchers into the field. But this alone is not the answer. Experience has convinced us that the funding strategy for ME/CFS must mirror that of other illnesses such as cancer research which obtains most of its revenue from private sources and ground-level fundraising. It is a huge task, but much can be achieved by a determined and collaborative ME community.

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ME Research UK receives no government funding, and relies on donations from other charitable trusts, and from donations and legacies from members of the public. As a registered charity, ME Research UK is tax-exempt, allowing us to realise your donation or bequest in full. If you would like to help ME Research UK by providing financial support for our important work

Make a donation online via charities Aid Foundation e-meresearch.org.uk fund-
ing service.

A Place for M.E.



Recently I was sent an email about a new project in Norfolk.
It reads:

Our purpose is to provide adapted housing and specialist care to those with M.E. This is a world first! The Chief Medical Officer has stated that the "improvement of their (Severe ME sufferers) care is an urgent challenge". This is because of their great suffering, poor quality of life, and social invisibility.

We hope to set up households of 4 people with severe ME to support one another and share resources. A Housing Association will provide a house with sound-proofed bed-sitting rooms, air-conditioning and wheelchair adaptations. 2 live-in carers, from the ME Care agency, will supply 10 hours of care to the household each day. We have also allocated 1 room in the household for respite care visits, for those with moderate ME to rest and recuperate.

We have made good progress with our plans: We have developed a relationship with a Housing Association and will put in an application to the Housing Corporation in 2008; we will also apply for grants to support our "Stay Home" respite care provision that we are working on - to allow families a break from the heavy duties of caring for those with severe M.E.

The website continues...

Four persons with ME, 2 very severely affected and 2 severely affected would join forces and resources to form an ME Household. This combination is the right balance of income and care needs to make the Household SELF-FINANCING; living independently within the community and maximising the benefits of their income. This independence, shared support and responsibility for each other would foster personal dignity and a sense of enablement



The financial projections that A Place has put together show that this model is viable! The 4 weekly income - using the lowest DLA Care rate for 2 householders and the middle rate for 2 - is £5,600. Expenditure comes to £5,050 and includes rent, food, heating, electricity, water, council tax, buildings insurance, telephone and broadband, tv licence, maintenance fund and 2 cats plus carers costs. The figures add up! An ME HOUSE would have 4 bed-sitting rooms with soundproofing, air-conditioning, darkened windows; every care taken to minimise sensory input. A home that is not hostile.

Also rooms for 2 live-in carers and even a room set aside for respite care.

They would be owned by a "benevolent landlord", perhaps a Housing Association. The house is an 8 bedroom guesthouse on the Norfolk Coast and its asking price is £150,000.

This is no dream: if we want this & are committed, it can be REAL.



This is a fabulous if very ambitious idea for the severely affected. To fund, purchase and manage a property is a huge undertaking but for the severely affected having the support of fellow sufferers plus the care required will be of huge benefit. It's a sad fact that not everyone has the family or a partner available or able to provide the care required and to have the option of "A Place for M.E." would make all the difference to their quality of life and the course of the illness.

More info at

Craig Woods

www.aplaceforme.info



Pass the Word

by Marly Silverman ImmuneSupport.com

New Educational DVD on Fibromyalgia - Watch It Online,

The Following Announcement was Issued February 2 to "Friends and Family" by Marly Silverman, founder of Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy ([P.A.N.D.O.R.A.](http://www.pandaora.org))

The Information Network Television (INT), a state of the art educational film production company with offices in Boca Raton, Florida, has released their Healthy Body, Healthy Mind video segment on Fibromyalgia (FM).

The video depicts the personal stories of several FM patients throughout the country, including P.A.N.D.O.R.A.'s founder Marly Silverman and South Florida rheumatologist Dr. Steven Croft.

Also interviewed were Dr. Don Goldenberg and Dr. Daniel Claw, and patients Andy Wold, Judy Stern, Lynne Matallana (President of the National Fibromyalgia Association) and Judith Becerra.

You can see the entire video at -:

www.itvisus.com/programs/hbhm/episode_903_UnderstandingFibromyalgia.asp

X-Party Group on ME.

Holyrood



Scottish GP Guidelines. Having previously been commissioned by the health department to produce guidelines on CFS/ME for Scotland but not having completed the commission, Action for ME (AfME) have received a revised commission to produce guidelines by the end of the financial year (March 31st). Carol Flack was engaged in December to carry out this task, and met the committee of the Cross Party Group on ME (CPG) in December as part of her preparation.

Dr Gregor Purdie had intended producing such guidance as part of his proposals for services for ME & CFS sufferers in Scotland, and, having previously discussed the parameters with SIGN and other interested medical agencies, is cooperating with Carol Flack in realising this project. Contacts have been made with most potential participants in the 3 reference groups envisaged as commenting on and guiding the development of the guidelines – (GPs, specialists & patient representatives) – though this remains incomplete and some professionals have indicated their inability to participate in the restricted time-scale.

To meet the first stage of the intended 3-stage development of drafts for the guidelines, Carol Flack put together a rough first draft using the existing AfME guidance booklet and other sources she had. This was circulated on Tuesday 22nd, in advance of the CPG meeting on Wednesday 23rd, and February 4th was given as the date for submission of comments.

CPG Meeting. The first full meeting of the CPG in this parliament was on Wednesday 23rd. The meeting was advised that the Scoping Exercise commissioned from AfME by the Health Department had been completed and would be available on the AfME website soon. Also, the Needs Assessment had started and was intended for completion in July.

Dr Gregor Purdie & Carol Flack assured the meeting that the first draft was not intended as the main basis for development of the GP guidelines, but only as a start to the process. Patient representatives stated that the timetable was too short to expect sufferers to manage proper participation, and it was agreed that an extension would be sought from the Health Dept. However, it was pointed out that an extension to the completion date would not necessarily include the extra funding required to extend the work involved.

Concern was also expressed about those intended members of the reference groups who hadn't yet been successfully recruited, and Gregor Purdie will try to make direct contact with those and elicit their participation. A further concern was expressed that hurriedly-produced guidelines would not surpass the standards of existing guidance, which could be licensed and distributed by the Health Dept – possibly at less cost.

The next full meeting of the CPG is set for April 23rd, which is after the existing deadline for the completion of the guidelines, so the CPG committee members will presumably be the main source of information to patient groups without direct access to a member of the reference group.

Garden Wise

Three members that haven't been to Garden Wise before joined us at the February Get-together.

They felt they had benefited from coming along. It is always good to meet, have a blether and make friends with others that are suffering in the same way.

People often say things like "Thank goodness, It's not just me" or "I thought I was losing my mind", "Well at least, I know now that I'm not on my own". It can also be good for carers, Giving them a better understanding of the illness.

Garden Wise meetings are mainly a social event, We talk about allsorts (not the liquorice variety!) holidays, family, weddings, pets, ect. Last time some of us did manage to squeeze in a few minutes discussion about the first draft of the new Scottish Guidelines on ME



Library



We have a small selection of books about ME/CFS/FM for members to borrow.

Janet Graham with the help of husband Chris brings them to the Garden Wise get-togethers.

There is no charge and books may be borrowed for up to a month.



The IIME International ME/CFS Conference London 23rd May 2008

Invest in ME. We again hope to provide platforms for the following -
Epidemiology - Diagnosis - Pathology - Treatments and Protocols for ME -
- Research - Nutrition - Care

The conference to be held at 2 Savoy Place, London. WC2R OBL, will again highlight the need for empirical evidence based on valid, modern and scientific diagnostic and treatment protocols. The conference will provide a chance to hear the latest news on ME from the most prominent speakers within the ME community— in ME Awareness Month 2008.

YOUR SHOUT YOUR SHOUT

Stress Management.

A lecturer when explaining stress management to an audience, raised a glass of water and asked 'How heavy is this glass of water?' Answers called out ranged from 20g to 500g. The lecturer replied, 'The absolute weight doesn't matter. It depends on how long you try to hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes.

He continued, 'And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on.' 'As with the glass of water, you have to put it down for a while and rest before holding it again. Whatever burdens you're carrying now, let them down for a moment if you can. Here are some great ways of dealing with the burdens of life:

Since it's the early worm that gets eaten by the bird, sleep late.
Always keep your words soft and sweet, just in case you have to eat them.
When everything's coming your way, you're in the wrong lane.
A truly happy person is one who can enjoy the scenery on a detour.
Drive carefully. It's not only cars that can be recalled by their maker.
Birthdays are good for you. The more you have, the longer you live.

Someone sent me this by e-mail, I rather liked it, Hope you do. Craig Woods

Astrological Light Bulbs

Author Unknown

How many members of your astrological sign does it take to Change A Light Bulb?

- Aries: Just one. You want to make something of it?
- Taurus: One, but just "try" to convince them that the burned-out bulb is useless and should be thrown away.
- Gemini: Two, but the job never gets done - they just keep arguing about who is supposed to do it and how it's supposed to be done!
- Cancer: Just one. But it takes a therapist three years to help them through the grief process.
- Leo: Leos don't change light bulbs, although sometimes their agent will get a Virgo to do the job for them while they're out.
- Virgo: Approximately 1.0000000 with an error of +/- 1 millionth.
- Libra: Err, two. Or maybe one. No - on second thought, make that two. Is that okay with you?
- Scorpio: That information is strictly secret and shared only with the Enlightened Ones in the Star Chamber of the Ancient Hierarchical Order.
- Sagittarius: The sun is shining, the day is young and we've got our whole lives ahead of us, and you're inside worrying about a stupid light bulb?
- Capricorn: I don't waste my time with these childish jokes.
- Aquarius: Well, you have to remember that everything is energy, so...
- Pisces: Light bulb? What light bulb?

[For those of us who know a bit about astrology, this is very funny indeed! From Janet \(Pisces\) x](#)

YOUR SHOUT YOUR SHOUT

Kiltie, Kiltie, Cauld Bum

Highland dress is widely worn
Both by young and old
But what's worn beneath the Kilt
The secret's seldom told

Dressed in his regalia
There's no smarter man than he
The only glimpse of flesh you'll get
Is of his knobbly knee

The skirl o' the bagpipes
At a highland dance
You might see a bare bum
But only at a glance

To help keep his kilt in place
There's something that is worn
It's like a hairy handbag
And this is called a sporran

Nae boxer shorts or 'Y' fronts
Or briefs of any kind
There's absolutely nothing
To cover his behind

Don't try and sneak a look
To see if a Scotsman's true
He might get angry
And show you his skean-dhu

So, what's worn beneath a kilt
I bet you all guess wrong
To show off a hairy bum
He wear's a tartan thong.

A.G Dumfries



Dear Norma & Denis

This letter is to tell you how much I enjoyed meeting yourselves and other members on Saturday. [Garden Wise 02:02:08] When I got home I was exhausted and in severe pain but still wishing I had come years ago. Since being diagnosed with ME I have found myself spending more and more time on my own.

It was good to be in the company of people who understand this awful illness. Being able to talk and listen to people that understand was a tonic. I would strongly recommend anybody suffering in silence at home to pop along
Many Thanks
Wendy [Fleming]

Thanks Wendy. We all enjoyed meeting you too.

Message from the Network

Thank you to all who sent Christmas cards and good wishes also messages of encouragement on Keeping up the good work.

Please remember we need you and would like to have as much input as possible for the newsletter from members

Sorry to hear that John Innes-Watt has been in hospital for operations and Jan Carter and her husband are not at all well.

To them and all members that are going through a bad time just now we send our best wishes and hope you have better health soon.

Take care.

Norma, Denis and the Committee.

HELP

LOCAL COMMITTEE CONTACTS
D&G ME NETWORK

If you are worried, stressed, feeling alone or fancy a chat don't hesitate to call any of the following :-

Craig (Lochmaben) 01387 811082
e-mail craig@dgme.co.uk

Norma/Denis (Lockerbie) 01576 204129
e-mail dennor@btinternet.com

Janet (Newton Stewart) 01671 403577
e-mail janetg_uk@yahoo.co.uk

ME RESEARCH UK
The Gateway, North Methven Street
Perth PH1 5PP, UK

Tel 01738 451234

E-mail meruk@pkavs.org.uk

Website enquiries editor@meresearch.org.uk

ACTION FOR ME

Information service and general enquiries, publications and information for young people.

TEL ; LO Call **0845 123 2380**
9.30am-5pm Monday to Friday
www.afme.org.uk

WELFARE RIGHTS HELPLINE

01749 330136

9-1PM Mon, Tues, Thurs
9-12.30 Fri

Website for children and young people

www.a4me.org.uk

ME ASSOCIATION

TEL 08707 443011

FAX 01280821602

www.meassociation.org.uk

The views expressed in this newsletter are not necessarily those of the D&G Network. We do not recommend treatments, but may express opinions.

25% ME GROUP 01292 318611

**CLOSING DATE FOR SUBMISSIONS FOR
SPRING NEWSLETTER
28th APRIL 2008**

Dates for your diary
or notice board

1st Saturday of every month meet at

Garden Wise in the conservatory between
2 pm and 3 pm

There will be a copy of the latest Magazine
showing on our table, for you to spot us.

If you carry a magazine as well we can spot you!

Garden Wise

Saturday March 1st

Saturday April 5th

Saturday May 3rd

Friday 4th April 2pm—4-pm

Lochthorn Library

Dumfries

Speaker Sylvia McCracken

Everyone Welcome



IF I GET LOST OR YOU CANNOT DELIVER ME PLEASE RETURN TO ;

**TURNER
LEAFIELD.SOUTH HAYRIGG.LOCKERBIE.DG11 1BJ**