

# Pathways

The newsletter of Leger M.E. Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.



The group of demonstrators being filmed by Sky News.



Trevor speaking to Di Newman from Peterborough

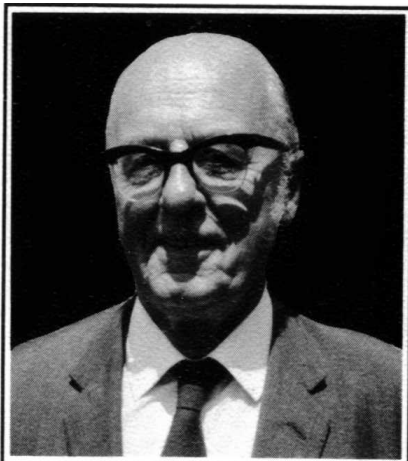


Members Trevor & Joyce

## M.E. Day Demo in London

As in recent years, for M.E. day, May 12th, Leger ME and MERSC's prolific campaigners Trevor Wainwright and Joyce Coggan went to London, campaigning on behalf of the area's M.E. sufferers. Trevor was in his 'Cell Block ME' Uniform. Because of the recent General Election it was not possible to mass lobby M.P.s as last year, but nevertheless Trevor and other people like him were in Westminster waving the ME flag. More details on the rear page in Trevor's Feature 'North of Doncaster'.

The late Dr. Melvyn Ramsey. At the time of the outbreak. He was consultant Physician of the Infectious Diseases Department of the Royal Free



Hospital He is the originator of the term 'Benign Myalgic Encephalomyelitis'. In later years the 'Benign' term was dropped.

## M.E. is 50 this year.

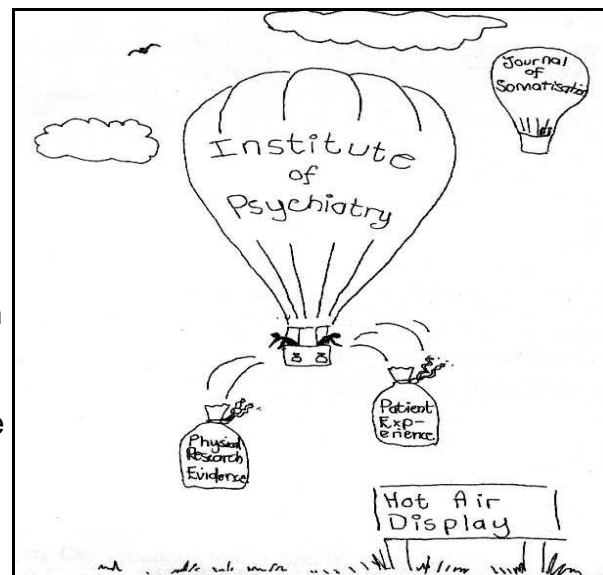
The name 'M.E.' was first used by Dr. Melvyn Ramsey in connection with the Royal Free outbreak and closure of the Royal Free Hospital.



On July 13th 1955, a doctor and a ward sister were admitted with an obscure illness. July 25th saw 70+ staff affected. The hospital had an epidemic of what appeared to be a virulent virus. The hospital closed until October 5th, although sporadic cases appeared up to the end of November. 292 members of staff were affected. Many were admitted to other hospitals. Although the hospital was full at the time, only 12 patients developed the disease. In other words the disease didn't affect those resting in their beds. It hit the workers. The people had pain (myalgia), brain problems (encephalitis), and spinal chord problems (myelitis), hence the name Myalgic Encephalomyelitis. There are still a number of patients disabled today from that outbreak. More on page 2.

## ***M.E. is Mass Hysteria ?***

The previous information is a précis of the opening two paragraphs of the report on the outbreak published in the *British Medical Journal* of October 19th, 1957, by the medical staff of the hospital who were concerned with the care of these patients. The clinical picture which they described was based on the findings in two hundred of these cases in which the diagnosis seemed certain, and in which the records were complete. No analysis was made of the remaining ninety-two cases and with the gift of hindsight this omission was to prove singularly unfortunate since they contained many instances of nurses who had succumbed to panic at the rapidity with which their friends and colleagues were going down with the 'mystery illness'. As a result of this, at a later date, Drs McEvedy and Beard were presented with abundant material for their 'mass hysteria' hypothesis.



Cartoon by Jenny Gilmore

In the late 1960s, the consultant staff at the Royal Free received a request from Drs McEvedy and Beard from the Dept. of Psychological Medicine at the Middlesex Hospital, for permission to peruse the records of the nurses involved in the outbreak of 1955. I was one of the many staff who saw no reason why this request should not be granted as we had nothing to hide. I think I am correct in saying that the only dissenting voice was that of the late Dr Helen Dimsdale, consultant neurologist: I was frankly puzzled at her attitude, but when I asked for an explanation she would only say "I think it is very possible that you will live to rue the day when you made yourself a party to this decision". No truer word was ever spoken.

In a first paper (*McEvedy & Beard; 1970a*) reasons were given for regarding the Royal Free Hospital outbreak as an instance of 'mass hysteria'. In a second paper (*1970b*) they argued that the fourteen outbreaks reviewed by Acheson (1959) contained features which justified a similar conclusion but they agreed that 'Los Angeles and other outbreaks associated with poliomyelitis cannot be considered such "pure" examples of mass hysteria as the Royal Free Hospital epidemic'.

Drs Dimsdale, Compston and Richardson and myself (*Compston et al., 1970*) immediately replied to this claim with a letter in which we stated that while the diagnosis of hysteria had been seriously considered at the time of the outbreak, the occurrence of fever in 89%; of lymphadenopathy in 79%; of ocular palsy in 43% and of facial palsy in 19%, rendered it quite untenable. Acheson, who had personal experience of the cases at the Middlesex Hospital in 1952, stated that they too had considered a possible diagnosis of hysteria but for similar reasons had ruled it out. Yet

### ***There IS life after M.E.***

One of our members, now recovered from M.E., dances with 'Movers and Shakers', the over-fifties dance troupe based at 'The Point'. Currently the troupe is rehearsing with English Touring Opera, in preparation for a community opera, "One Breath", celebrating the life of Mary Queen of Scots. Nine other groups, including children and young people will also be involved. A professional singer will play the role of Mary.

There will be two performances of "One Breath", the first on June 17th at The Dome, Doncaster and the second on June 18th at Manor Lodge Castle, Sheffield, where Mary was imprisoned for many years. Both performances start at 7.0 p.m. and tickets are modestly-priced at £2 for adults and £1 for children. The Sheffield performance is in the open air so the audience is asked to take something to sit on.

For further information visit [www.englishtouringopera.org.uk](http://www.englishtouringopera.org.uk)  
For tickets, please telephone:-  
The Dome, Doncaster 01302 370999  
Manor Lodge, Sheffield 0114 2496000

neither McEvedy or Beard had any personal experience of the disease. Their interest had been aroused as a result of an outbreak in their own hospital in 1952 which had been reported by Acheson(1954).

All the outbreaks, together with the many sporadic ones which constitute an 'endemic' basis for the disease, are bound together as a single infectious disease entity. by the almost unique form of muscle fatiguability which may in some instances result in permanent physical incapacity. I consider the McEvedy and Beard hypothesis to be totally untenable, and it is a matter of regret that it was ever put forward, nor can one explain why it was accepted so readily by the profession as a whole. The records were there to be studied at the time McEvedy and Beard published their papers and I can only hope that my account will stimulate others to check the facts for themselves. So radically did McEvedy and Beard influence medical opinion that, when I have attempted to put the case for an organic explanation of the disease to younger present day consultants, I have encountered an attitude of pitying disbelief and the remark. "Oh but that was long ago shown to be the result of mass hysteria". I can only say that a whole generation of unfortunate victims of this disease have been driven to despair by the failure of their doctors to recognise the validity of their symptoms.

Louie Ramsey wrote in the 21st Anniversary MEA 'Perspectives' in 1997 "For many years, I watched my father battle with the unbelieving; he must have felt as much as the ME sufferers themselves as setback followed setback". I personally find the position hasn't really altered that much today in 2005.

*'Gwen Smith' was a victim of the 1955 outbreak, still affected with M.E. today. The recent Chief Medical Officer's Report should finally see the Mass Hysteria Hypothesis finally discredited.*

*There will be a demonstration outside the Royal Free Hospital, London, on July 14 to mark the 50th anniversary of the outbreak of 'Royal Free Disease'. The demonstration is being organised by Trevor and former speedway star Gary Frankum. Would anyone interested in attending please contact Trevor directly on 01977 554273. - Mike*

## Heaven Sent

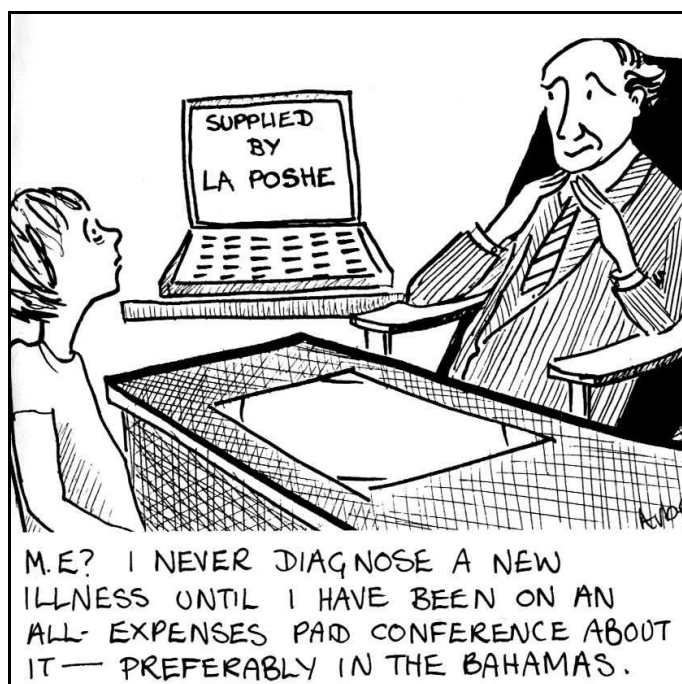
From behind curtains I watch people going by  
Little realising how on others I have to rely  
As in my bed cocooned I do lay  
Depending on others each and every day

In the distance I see birds in flight  
They have no inkling of my plight  
Over gardens and rooftops on the wing  
They fly with such energy zest and zing

How I long to be out and as free  
To be rushing around with excessive energy  
Oh the joy of doing everyday things  
Without the restrictions that my body brings

There will come a day I have no doubt  
When I'll be capable of going out and about  
But until that day I must be content  
To await the freedom that will be heaven sent

© **Rhona Pook**





## The BT Digital TV Freeview Adaptor.

Recently on the news we heard that the old analogue T.V. signal will soon be switched off. Unless you subscribe to Telewest, Sky, or have a Freeview TV already, then you will have to buy a Freeview adaptor. With digital TV there are twenty plus channels besides the five main ones. There are many Freeview adaptors on the market starting from £40 up. What makes the BT adaptor stand out from all the others is that it is also an internet and email terminal. To access email and the internet, a personal computer is usually needed, with appropriate software, which costs from around £350. The cost of the adaptor is £69.99 plus postage from the BT online shop. This represents a considerable saving if you just want Web-access economically, or wish just to try it out before buying a PC.

Recently, a member of my family lost his mobility, and to enable him to get out and about online, I ordered one of these units. The setup instructions were clear enough, and once hooked to a TV and telephone line, the unit set itself up. The unit downloaded the latest



*When the adaptor arrived it came with the usual T.V.-type remote control, plus a remote keyboard. There is no mouse, you have to navigate via a green square using the arrow keys on the keyboard. This is easier for people with hand tremor.*

BT provide their own support-site for the unit and their own Point Of Presence (POP) for dial up access. Many of the BT site functions can be accessed by a single dedicated key on the top row of the keyboard. Once set up, I could access the web and internet via the BT POP. But there was a catch. The calls are charged at BT's local rates 5.5p per minute. Online time passes quickly, and you're looking at a telephone bill of £3.30 per hour. There are, however, other internet service providers which charge fixed monthly rates. I chose to register with Wanadoo, formally Freeserve, because they charge £15 per month and support the low resolution screens. I had to set up the unit manually via a phone call to Wanadoo, but once set up everything worked fine.

We ordered clothes from Kay's catalogue site, and a grocery order from the local Tesco store. Online-ordering availability depends on your postcode. Other supermarkets e.g. Asda, also provide this service. To order via the internet you need either a credit or debit card, preferably from a bank like the Halifax who will guarantee internet security. We have decided to restrict ourselves to websites of well-known stores, for security reasons.

There are many more features of this unit too numerous to mention here. You can get further information about it from B.T. online shop, <http://www.shop.bt.com/invlt/011613> or ☎ 0800 328 9654. At the time of writing, the adaptor described was out of stock, but the next model up, the BT iPlayer+, with the same functionality and extra features was available for £79.99. – Mike



*Onscreen menus and information are a feature of digital TV*

software from the BT site. Using your T.V. as an internet monitor is a compromise, because the resolution is 640 x 480 pixels which was the standard 15 years ago. Now, most PC monitors are around 1000 x 2000 pixels and so are capable of displaying far more detail on bigger screens. However, there is an increasing trend to access the internet on handheld PCs and mobile phones, so many web site providers are providing a small-screen version of their sites. There is even a USB socket for a conventional PC printer or other USB devices. As the unit is a ROM terminal, with no hard disk, it means that many of the viruses and other internet security problems targeted at PCs don't affect the adaptor.



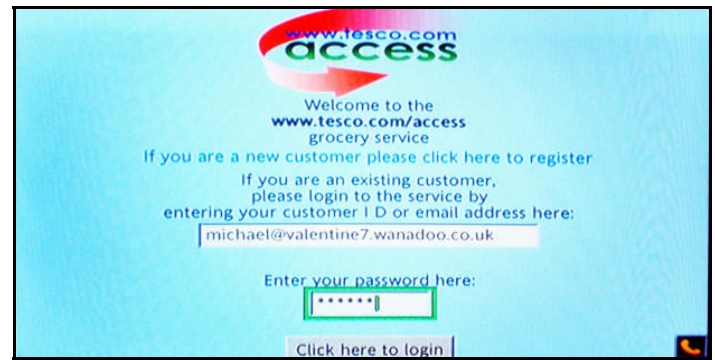
*Wanadoo's home page.*



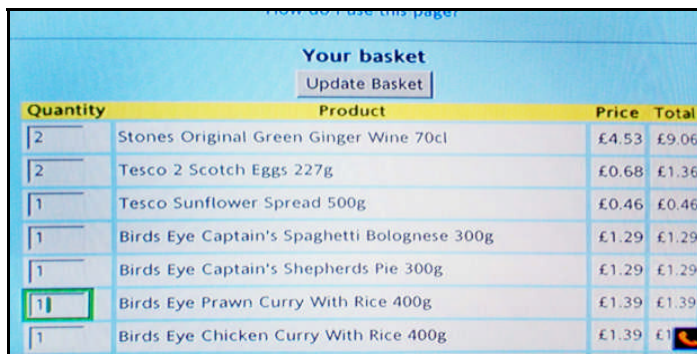
## Example live pictures taken from the TV screen of the BT Freeview Adaptor.



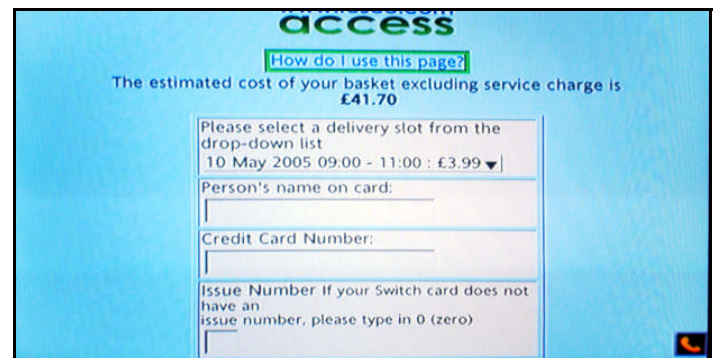
1) Pressing the WEB button prompts you to type the web address. The small phone at the left hand corner indicates the data traffic



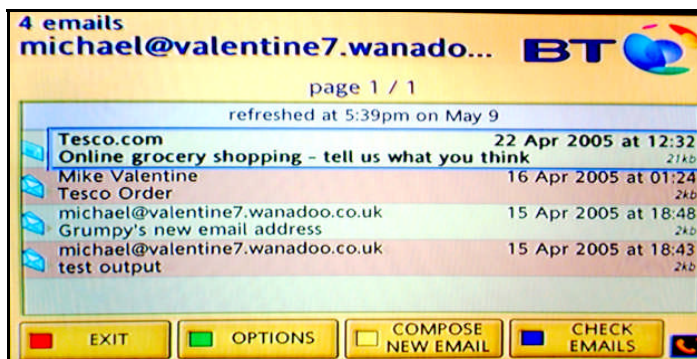
2) This leads to the gateway page. To use the site you have to register, and choose a password. After that you just log in and your account is displayed..



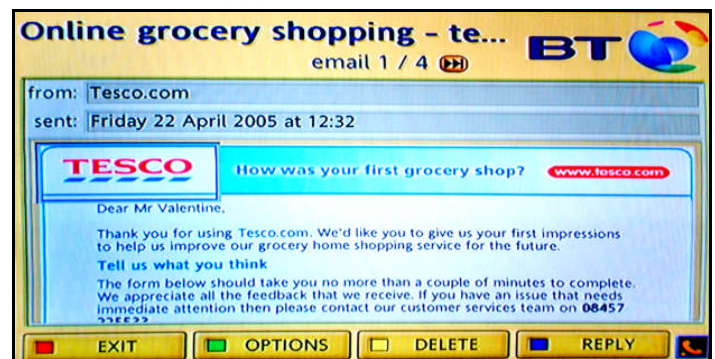
3) As in a real supermarket you visit the aisles and shelves, and put your shopping into the 'basket'. Previous orders can be recalled for quick access.



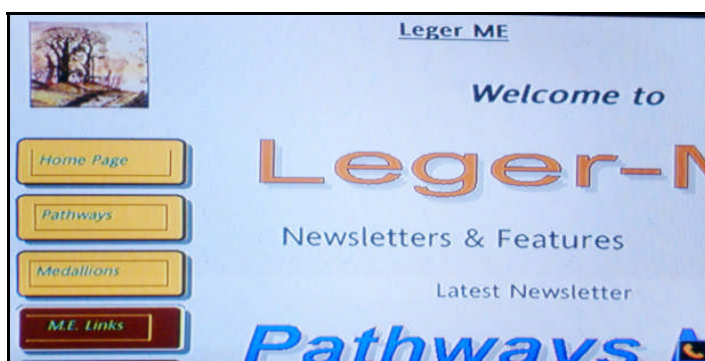
4) Just like in a real supermarket you go to the 'checkout'. Here credit or debit card details are taken, and a delivery slot is arranged.



5) Pressing the Email key brings you to this screen. You just choose the email to view by pressing the arrow keys, and hit the 'enter' key.



6) In this case, the email was from Tesco asking us for feedback on their web ordering service. You can choose to delete or keep the email.



7) The Leger M.E. website is a high resolution site, and the unit can only display a part of the picture at a time. You have to scroll the picture with the arrow keys.



8) This is the web version of Pathways no. 3. The whole page has to be scrolled as is also the case with conventional web-browsers like Outlook Express.

## ***Incapacity Benefit Reform ( Source BBC )***

With the return to power of Tony Blair's Labour Government, The Queen's Speech announced that a bill to reform incapacity benefit to "facilitate a return to employment" would be laid before Parliament. The job of reforming this Benefit has been given to David Blunkett, the well know blind M.P. for Sheffield Brightside who is in charge of the Department of Work and Pensions. Hopefully this will result in sensitive handling of a complex issue. The benefit paid to 2.7 million claimants now costs about £7 billion a year. The government has announced it is to be overhauled, to remove disincentives to return to work, Incapacity Benefit is to be scrapped along with automatic rises in payments for claimants after six months and a year. The scheme will not affect existing claimants, who will continue drawing Incapacity Benefit. For new claimants, it will be replaced with:-

**A Holding Benefit** - the same as the £55-per-week Jobseekers' Allowance would be paid until the claimant was assessed by a doctor. After that the claimant would move to:-

**Rehabilitation Support Allowance** - a flat rate of about £55 but extra money for those trying to return to work, or:-

**Disability and Sickness Allowance** at more than current Incapacity Benefit rates, for the 20% of people with the worst disabilities. These claimants would also get extra money for attending work-focused interviews, training and rehabilitation.

The scheme aims to ensure that the "nine out of 10" claimants who want to get back to work quickly are able to do so. Ministers say they want those who can work to do so. Punishment is not the aim of the shake-up of benefits paid to sick and disabled people, new Work and Pensions Secretary David Blunkett has said. The government announced earlier this year that it wanted to reform Incapacity Benefit and get about one million claimants back to work. Promising to consult widely about the changes, Mr Blunkett said: "Let's not patronise people, let's support them." "It is about 50 years on taking a real look at what people want in their own lives." Welfare reform has provoked Labour backbench rebellions in the past. With the Party's majority in the House of Commons cut to 67, there is now less scope to resist such revolts. Mr Blunkett said: "Don't believe for a minute that the reform of the welfare state for the 21st century is somehow punitive. It is not."

The Disability Rights Commission says the Government risks derailing Incapacity Benefit reform with negative media images of disabled people. DRC chairman Bert Massie is urging the Government to stop portraying claimants as "work shy". The DRC is one of a number of groups which, while welcoming measures to help disabled people to find jobs, is concerned that tough talk from ministers will have an adverse effect. "Characterising people on incapacity benefit - a million of whom say they want to work again - as work shy, will hardly aid their employment prospects" said Mr Massie.

"If the Government is serious about supporting disabled people back into work, then the energy it has exerted in sounding tough should be turned toward the real challenges - tackling the barriers to work, ending employer discrimination and investing in disabled people's skills."

Leonard Cheshire's Jon Knight said: "The government's policies could end up making disabled people, already some of the poorest in society, even poorer. "People whose condition causes them pain or fatigue should not be forced to look for employment."

Scope's Chief Executive, Tony Manwaring, said this was particularly important for, "those with high support needs and those who have been out of work for long periods, who in the past have found themselves penalised rather than supported". "We look forward to working with the Government to ensure the welfare benefit system supports disabled people to live independently and free from poverty, rejects segregation and enables disabled people to exercise choice and control over every aspect of their lives."

"RADAR believes strongly that disability does not mean 'cannot work'," said Chief Executive, Kate Nash. Ms Nash thinks that the current system unhelpfully compartmentalises disabled people into those who can and cannot work. "It's all a matter of the right person, in the right job, with the right support," she said.

## **Scottish scientists find 'Key To Curing ME ?'**

*Adapted from a feature by Ian Johnston, Scientific Correspondent of 'The Scotsman'*

A treatment for the debilitating condition ME could be available in as little as a year after groundbreaking Scottish research. A Glasgow University team has discovered a malfunction in sufferers' genes which appears to prompt their immune system to "work overtime", making patients extremely tired. The lead scientist, Dr John Gow, said a cocktail of drugs could be used to "turn off" the genes, allowing patients to live "a fairly normal" life. The University has already patented the genes involved as a means of diagnosing the condition, also known as Chronic Fatigue Syndrome (CFS), quickly and cheaply. The disease has gradually gained acceptance and in 2002, Professor Sir Liam Donaldson, the Chief Medical Officer for England and Wales, said that "CFS/ME should be classed alongside other diseases such as multiple sclerosis and motor neurone disease".

Dr Gow, a senior lecturer in clinical neuroscience at the University, mapped all 33,000 genes in CFS sufferers and then compared them with the genes of healthy people. Dr Gow, who works at Glasgow's Southern General Hospital, said they found CFS sufferers had a particular kind of "unusual gene expression". "This means the genes are switched on or off at an inappropriate time. "We have identified a number of genes that are wrongly switched on," he said. "It looks like the immune system is working overtime when it shouldn't be, making the patient tired."

Every cell in the body contains the same 33,000 genes, but only about 10 per cent are actually doing anything at any one time. There are genes related to the production of liver proteins in brain cells, for example, but these should be "switched off" because liver protein is not required in the brain. Drugs can be used to control chemical pathways that act on the genes, and Dr Gow said he had identified ones that could be used to regulate the over-active genes in CFS. These drugs are already on the market for other conditions and could be given to CFS sufferers within a year if tests prove positive. Dr Gow stressed that the drugs had to be tested in practice. "This is not a major breakthrough yet, but it is a big step forward," he said. A prototype diagnostic testing kit has already been developed which would give doctors "a yes or no answer" about whether someone had the condition. Currently it takes about six months to make a diagnosis.

However, Dr Gow said he was currently "going nowhere" because his funding had run out. Dr Neil Abbot, of the medical research charity MERGE, which works on ME, said: "This is very exciting work. The analysis of genes is one of the most interesting modern areas of research which has the potential to come up with a cure, but this may be in the long term."

### *Comment.*

*The CFS Research Foundation has been funding similar work by Professor S. Holgate and Doctors Wendy Barclay and Robert Powell on specific gene expression, similar research which could lead to a diagnostic test. LME trustee Trevor Wainwright and our Sister group MERSC have raised several thousand pounds for the CFSRF. (See Pathways No.2)*

*When I was first diagnosed in 1993, it was suspected that the M.E.'s immune system was somehow uprated, as if it were trying to find a virus that it somehow couldn't latch on to. Consultant Dr. P. Stanley of the Leeds Fatigue Clinic explained that the fatigue itself was explained as being over production of certain cytokines, which put the body into a flu like state to fight a virus. This gene expression research has only been possible with the recent emergence of DNA technology. It's reasonably certain that this research could lead to a diagnostic test, but this would be years away. As to a treatment, I'm not so certain. In cystic fibrosis there is a single error in the DNA sequence. It was thought that a single error could easily be treated by Gene Therapy. However, research has produced mixed and contradictory results. My feeling is that ME/CFS is more complicated in origin, and it won't be that simple to find the solution.*

See <http://news.scotsman.com/scotland.cfm?id=550752005> - Mike



## ***Depression Issues and M.E.***

There are some doctors who can't tell the difference between ME/CFS and depression, which are two completely different health problems. However you have to remember that someone can suffer from M.E. as well as depression at the same time. Some people who suffer from endogenous depression first, then get ME, will tell you that the two diseases are completely different. Research at the Leeds Fatigue Clinic shows that about 30% of people with M.E. will have reactive depression due to having a chronic illness. The same proportion applies to patients with Multiple Sclerosis and Arthritis. By treating the chronic illness, the depression can be lifted. Whether the depression is reactive or endogenous, the typical antidepressant treatment will work. There is a version of depression, which is known as Manic Depression (Bipolar Affective Disorder) in which Mania and Depression can alternate in phases, and which doesn't respond to the usual antidepressants. It has different characteristics to endogenous depression, and is sometimes mistaken for M.E. This is why it is important that patients attend CFS clinics such as the one in Leeds where they have the expertise to sort these things out. You also have to remember that where mental health issues are concerned, very often clinical issues are blurred, and it is not possible to come to an immediate diagnosis.

Very often trials with drugs and negotiation are part of the diagnostic process. The fact that Seroxat or Prozac doesn't work or produces side effects, supports a diagnosis of M.E. One of the most useful treatments for ME is a tricyclic like amitriptyline, which given in a low dose (2 –10mg). This is effective in relieving many symptoms of ME, including pain. An antidepressant dose would be 25mg three times daily, or higher. This will usually cause side-effects in ME's e.g. blurred vision, dry mouth and drowsiness.

Recently the National Institute for Clinical Excellence (NICE) published guidelines for the treatment of depression in adults. It describes a stepped-care approach to the recognition and coordinated treatment of depression, taking into account the severity of symptoms, individual patient circumstances and preferences. Most patients who visit a doctor with depression in general practice have mild depression. For these people a 'watchful waiting strategy' is recommended, with a follow-up appointment being made normally within two weeks. Antidepressants should not be prescribed initially in people with mild depression, as any benefit is unlikely to outweigh the risk of unacceptable side-effects. Interventions that can be considered in mild depression include guided self-help based on cognitive behavioural therapy (CBT), and other brief psychological interventions.

Where depression persists, or is assessed as moderate or severe, antidepressants are appropriate. More prolonged psychological treatments should be offered to those who refuse antidepressant treatment, or who do not respond adequately to a range of other treatments (e.g. antidepressants and brief psychological interventions). All patients receiving antidepressants should be informed about the possibility of discontinuation withdrawal symptoms, if they are stopped abruptly. Patients should be referred to mental health care specialists for evaluation and treatment if they are resistant to treatment, if their depression is atypical or psychotic, or if they are at considerable risk to themselves or others.

As there is little clinically meaningful difference in efficacy between antidepressants, choice should take into account their side effect profiles, patient preferences and cost. NICE recommends SSRIs for routine use (fluoxetine and citalopram are reasonable choices) rather than tricyclics, as they are less likely to be discontinued because of side effects. Because of concerns over cardio-toxicity and toxicity in overdose, venlafaxine should be initiated and supervised only by specialist mental health professionals, including GPs with a Special Interest in Mental Health. Venlafaxine should not be prescribed for people with pre-existing heart disease. Other treatments that should be initiated only by specialists include dosulepin (dothiapien), phenelzine (a MAOI), combined anti-depressants and lithium augmentation. As far as treatment for depression in children goes, the evidence is inconclusive.

On the table over the page I have compared the main features of ME/CFS, Depression and Manic Depression. Sometime people may have a mixture of all three problems. Please note that this is for information and any queries should be directed to your G.P. or M.E. specialist. It is not wise, (even for doctors) to try and assess your own mental health issues - *Mike*.



## ***Comparison of the Main Characteristics of M.E. and Depression***

<b>Symptom</b>	<b>ME/CFS/PVFS/FMS</b>	<b>Depression</b>	<b>Manic depression</b>
1) Exercise.	Makes patients much worse. Rebound may take several days to show. May not complete activities due to exhaustion or pain.	Agitation or slowing of movements. Fatigue or low energy but exercise beneficial in relieving symptoms.	Overactive to point of exhaustion. May start many activities, but not complete them.
2) Muscle tenderness and pain.	Common.	Unusual.	Unusual.
3) Response to alcohol and anti-depressants.	Makes some patients worse even in low doses.	Beneficial at antidepressant doses.	Respond only to antipsychotic drugs
4) Sleep disturbance.	Biological clock is late. Typical 6 hours but may be 12 in children. Sleep late and wake late.	Disturbed, usually early morning wakening.	Very little in manic phase, but oversleeping in depressive phase.
5) Adrenal function.	Usually depressed, especially HPA axis.	May be associated anxiety, with raised levels of cortisol.	May be associated anxiety, with raised levels of cortisol.
6) Immunity.	Uprated, atopic or poor immunity, with recurrent infections.	Not a feature.	Not a feature unless emaciated due to lack of self care.
7) Neuro-psychometric.	Short term memory loss, nominal aphasia Loss in mental agility.	Poor concentration or indecisiveness.	May speak and say a great deal. Many change to flights of ideas and illogical thought trains.
8) SPECT and PET Scans.	Diminished metabolism in the brain stem, medial and frontal lobes of the cerebral cortex.	Diminished metabolism is more widespread and the frontal lobes are chiefly affected.	Depends on manic or depressive phase
9) Appearance.	Usually minimal attention, unless special circumstances.	Low self esteem.	May wear odd assortment of clothes often of bright colours.
10) Mood.	Usually optimistic, but frustrated by fatigue. Some patients may show emotional lability. No loss of pleasure.	Low self confidence. Guilt or self blame. Suicidal thoughts or acts. Persistent sadness or low mood. Loss of interest in pleasure.	Appear cheerful and optimistic alternating to irritable and angry.
11) Food.	May be sensitive to certain foods.	Poor or increased appetite.	Eat greedily with little attention to manners.
12) Sexual activity.	Interested, but cautious due to exhaustion.	Depressed.	Increased desire to the point of uninhibited behaviour.
13) Hallucinations.	Absent.	Not usually present.	Sometimes voices

***Water is Just Water - Isn't It? By Richard Hawkins***

*Adapted from Kirklees Independent Support Group Newsletter February 2005.*

For some reason, but please don't ask me to explain why, I calculated earlier this year that at the time I was consuming between two and three times more liquid in a year than I put petrol in my car. No, my car is not particularly economic and it's not because I was hardly using my car, but more to do with me drinking a lot of liquids (doctor's recommendation!).

Over two litres a day of that liquid is bottled natural mineral water. Like me, you probably thought that most bottled waters were much of a muchness. I usually buy my mineral water in bulk from a particular supermarket where I do my major shop, but one day I purchased a bottle elsewhere and was surprised at the difference in taste. My inquisitive mind prompted me to start reading the 'mineral analysis' information printed on the labels of bottles of water and I was amazed at the differences. I looked at ten brands at random; all were 'still natural mineral water' and the details are shown in the table on the page that follows.

Whilst I am not a chemist, the differences are clearly significant and presumably depend upon the water's source. A few notable differences between brands are:

- Celtic Spring water from Powys in Wales has over 10 times as much sodium as the waters from Scotland - a difference you can clearly taste. Some healthcare practitioners recommend choosing a brand with a sodium level less than 30mg per litre.
- Evian from France has nearly 20 times as much calcium as Deeside water from Scotland, but also a relatively high level of magnesium. According to scientists, a high calcium level can lead to calcification in soft tissues and arteries particularly if there is not enough magnesium present to allow the calcium to be properly absorbed.
- Nitrate levels differ even more widely with two of the brands notably higher than the rest and one even stating zero.

You may conclude from all this that it is better to stick to tap water. It's certainly much cheaper costing approximately 0.006p a litre. However, despite Yorkshire Water's assurance of the purity of its tap water, there are conflicting claims that tap water contains traces of synthetic chemicals used in the purification process. These commentators also claim that the purification process cannot remove some of the residues used in today's society.

Interestingly, Yorkshire Water last year campaigned the slogan 'Best Served Chilled' to encourage more of us to drink tap water instead of bottled water. However, most food and drink experts claim that true taste is most apparent near to ambient temperature. Interestingly, the labels on most bottled waters also state 'Best Served Chilled'. Perhaps no suppliers of water want us to realise the true taste of their product. Clearly it's all a matter of personal choice and budget.

Footnote: 'Naturally light in minerals, clean and delicate to the palate with a light and fresh taste that also helps to improve mental awareness was the description on the menu of the Park Lane Restaurant in London's Marriott Hotel - for bottled water!

***Summer Canal Cruise, Sunday 24th July.***

Numbers are limited, so please book early to avoid disappointment. The cost will be £10 per person and will include refreshments midway. Please contact Mike on 01302 787353 or [mike@leger.me.uk](mailto:mike@leger.me.uk) for further details or to reserve a place.

**Still Natural Mineral Water** *Mineral Analysis of Random Sample (mg per litre)*

BRAND	Caledonian	Stretton Hills	Celtic Spring	Volvic	Buxton
SUPPLIER	Sainsbury's	Co-op	Mongomeryshire Water	Danone	Buxton Mineral Water
SOURCE	Lennoxtown	Shropshire	Powys	France	Peak District
Calcium	27.0	48.0	47.0	11.5	55.0
Magnesium	6.9	9.3	5.5	8.0	19.0
Sodium	6.6	13.0	65.0	11.6	24.0
Chloride	6.4	21.0	48.0	13.5	37.0
Nitrates	<2.5	15.0	0.0	6.3	<0.1
Fluoride	<0.1	<0.1			
Sulphate	10.6		35.0	8.1	13.0
Bicarbonate	103.0		310.0	71.0	248.0
Potassium	<1.0	1.2	10.0	6.2	1.0
Silicate	7.6			31.7	
Dry Residue	117.2		350.0	130.0	280.0

BRAND	Highland Spring	Eden Falls	Evian	Deeside	Malvern
SUPPLIER	Highland	Asda	Danone	Deeside Water Co.	Schweppes spring Ltd
SOURCE	Perthshire	Cumbria	France	Deeside	Worcester
Calcium	35.0	27.0	78.0	4.0	35.0
Magnesium	8.5	4.0	24.0	3.0	19.0
Sodium	6.0	17.0	5.0	6.0	15.0
Chloride	7.5	23.0	4.5	9.0	39.0
Nitrates	<1.0	25.0	3.8	<3.0	8.0
Fluoride		<0.1			
Sulphate	6.0	6.0	0.0	6.0	35.0
Bicarbonate	136.0	41.0	357.0	26.0	123.0
Potassium	0.6	2.0	1.0	2.0	1.0
Silicate			13.5		
Dry Residue	136.0	159.0	309.0	60.0	228.0



## ***Disability Living Allowance Issues.***

Most of our members with M.E. should qualify for this state benefit. It is a non contributory benefit. This means it does not depend on National Insurance Contributions. For purposes of assessing Income Support and Council Tax it is ignored. There are thirteen levels of payment from £15.55 to £99.55. One of our members gets this top rate, but most are somewhere between. If someone qualifies for the top rate of mobility, you automatically are entitled to a Blue parking badge, free road tax and the Motability Scheme. People over 65 cannot qualify for DLA, but can apply for a similar benefit, Attendance Allowance.

Very often on the helpline I find that members have been refused this benefit who should be receiving it. Most people who fill out the form themselves do not fill it in sufficiently well to obtain their full entitlement. The main reason is that it is a twenty six page plus document, and the questions asked are of a general disability nature and not specific to M.E. Once a form has been submitted usually the DWP will write to the claimant's doctor for a report. In many cases the doctor's report is lacking in the sort of information needed to substantiate the claim. This usually means that a doctor is sent out acting on behalf of the DWP to examine the claimant at home. Many of these doctors do not have the skill to assess someone with ME, and very often they do not find enough evidence to justify the claim. This is quite common. The only way to rectify the problem is the appeals process, which usually results in a tribunal.

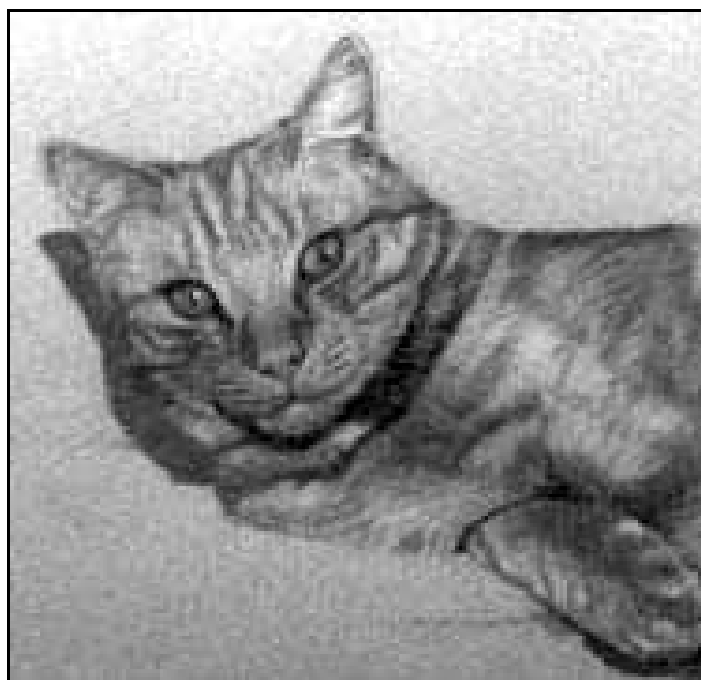
Leger ME have the resources to assist members at all stages of the application process from form fill-out to tribunal representation in association with the Orchard Centre. Anyone considering applying for DLA should contact me on 01302 787353 for further information. It is important that the application is presented completely, because if not any evidence presented later on cannot be considered in retrospect or back dated. This has resulted in several cases going to tribunals, and although being won, nothing could be awarded. A similar service can be obtained from the Citizens Advice Bureau, Dial, Doncaster Carers Partnership or Welfare Rights (Old Guildhall Yard). *Mike.*

## ***An Independent Medical Assessment Service***

I was speaking to Jenny Gilmore from the York Group. She has told me that Dr Wood, Consultant Immunologist at the Chronic Fatigue Clinic in Leeds will do a consultation and a letter for the Benefits Agency for £125 on a private basis. Dr Wood will need a referral letter from your GP and advises a diagnosis of CFS from the Chronic Fatigue Clinic first helps in his diagnosis. This needs to be stated in the DLA form, and you should say that you are seeing an independent specialist for assessment. For an appointment Tel. BUPA Leeds (01132) 185908.

*Brian Ashworth from the Orchard Centre tells me that the BA decision makers are instructed to take the opinion of their own appointed doctor above any other. Personally I think such an independent assessment would only be of value if there were difficulties with the GP or if the case went to a tribunal.- Mike*

*No, this isn't Marmalade. It is a portrait by Jenny Gilmore. She offers an animal portrait service 'Pets in Pastel' from £40. Pet portraits using pastel are popular with many pet owners. Pastels are a form of dry paint, which give an individual texture to a portrait which cannot be replicated in a photograph. For a portrait or gift voucher, including p & p and £5 donation for ME Research Tel:(01904) 655911 or. email jenny.gilmore@getreal.co.uk. Samples in colour of her work can be seen on:- [www.pets-in-pastel.org.uk](http://www.pets-in-pastel.org.uk).*



## ***The Biochemical Pathophysiology of Chronic Fatigue Syndrome. Follow Up***

Following Dr. Myhill's feature in Pathways No. 3, I wrote to Dr. Myhill asking 'How could we prove that this mechanism is present in me (Mike). The answer that came back was to test blood levels of SODase, a measure of antioxidant status, CPK levels, an indication of muscle damage, and NAD levels, a symptom of mitochondrial failure.

These tests are available privately, but on principle I decided to see my G.P. first, to see if they could be done free on the NHS. Only the CPK is a routine NHS test. So I duly presented myself to the practice nurse, and the sample was sent off. That came back normal. This implies that I do not have any muscle damage. In my next consultation with Dr. Myhill, she took blood samples for NAD and SODase. The SODase came back normal. This should be the case, because I'm receiving B12 injections, which it is an antioxidant. However the NAD came back borderline. That surprised me because I'm taking a multivitamin supplement with B3 at three times the recommended daily dosage. B3 is a precursor of NAD. Dr. Myhill recommended B3 as a large dose of Niacinamide 500mg three times a day. This strength is sold without restriction in massive quantities in the USA. However my G.P., wants to be a little more cautious. B3, although a vitamin, in big quantities is effectively being used as a drug. I am a diabetic and there is a family history of liver disease. So he wants to start me off at a low dose and work up, taking frequent liver-function tests and tests of blood uric acid. B3 can cause hypoglycaemia (see Pathways No. 3), liver abnormalities and gout as side effects. The implication is that I if take a high dosage of B3, and it has proven benefit, then it implies that liver-function tests should be carried on a regular bases.

Anyone thinking of supplementing with B3 should be aware that niacinamide is also called nicotinamide. There is another form of B3 known as nicotinic acid. This has an embarrassing side effect of causing blushing.— *Mike*

### ***Reminder To Pathways Subscribers.***

This edition of 'Pathways' is the fourth edition. We at Leger ME hope you have enjoyed and found the contents informative. The bad news is that Anne, our Treasurer, tells me that in order to cover costs we need to increase the minimum donation to £7 to receive Pathways and access Linking Up. The main reason for this is the recent increase in the cost of postage.

### ***Annual General Meeting***

The Annual General Meeting will take place on 23 August at 7.30 p.m. at 8 Fothergill Drive, Edenthorpe, Doncaster, S Yorks., DN3 2TL. Details are available from myself (01302) 787353 or from any committee member.

### **BUTTERNUT SQUASH AND SWEET POTATO SOUP**

(Serves 4)

6 – 8 cups water  
1 vegetable stock cube  
one butternut squash  
1 cup sweet potatoes, cubed  
1 cup carrots, cubed  
6 – 8 onions, sliced  
1 handful parsley  
1 clove garlic  
sprinkle of pumpkin and sesame seeds  
(optional)

Add the stock cube to the water and bring to the boil. Add the squash, sweet potatoes, carrots and onions to lightly boiling water for 5-8 minutes until tender but firm. Take away from heat and add the parsley and garlic. Blend in a food processor. Soup may be thicker or thinner depending on the amount of water used. Garnish with pumpkin and sesame seeds.

#### **Tip**

To make the Butternut Squash easier to cut up it is better if you pierce the flesh several times and boil in a pan for 15 minutes. Leave it to cool. The skin and flesh will have softened and it will make it much easier to cut and peel. *Anne*

***North of Doncaster, May 12th . Personal Comment by Trevor Wainwright***

Myself and Joyce travelled to London by bus. We were assigned two escorting Police Officers before making our way to the Department of Health (DoH) where a small but optimistic group, plus a film crew from Sky News were waiting for us. The first port of call was the Department of Health to hand over the first presentation. We continued to demonstrate. So the filming for Sky began from various angles. In the meantime we learned that Gary and Dr Puri had been interviewed on Sky News. Dr. Puri came over as positive about ME. This was pleasing, particularly as Gary had doubts about him with his being a psychiatrist. We had inquisitive people coming over and enquiring. We explained that we were the people at the sharp end, those involved where the illness mattered most, being Carers or Patients.

The next call was to the Medical Research Council (MRC). We flagged down a taxi the driver of which seemed to have no qualms about picking up what looked like a member of Band on the Run. Our destination given, off we went, pulling into Park Crescent he asked "whereabouts?" We said look for a group of people. "There, it's Gary," said Joyce, as we looked at a small group of people outside one of the buildings, so dropped off, fare paid, we went to meet the second small but happy band. I thought of the presentations in my backpack, I was pleased but felt a touch of sadness as in the presentation, apart from my covering letter, there was nothing from where I lived, Castleford and the Five Towns, oh yes, there had been letters sent to the local media one had been published in the early days but follow up letters had not, one paper not printing anything at all, 'gee thanks, for nothing' I thought 'still a third rate illness to some' I thought. Gary already waiting at the MRC was over the moon about the interview. We went through the doors of the MRC. The two receptionists looked in surprise at my prison suit until I explained why. Sarah the press officer of the MRC arrived; we were led into a room where the presentations were handed over. We had a brief discussion. Sarah said she would ensure they got to the desk of Professor Blakemore.

Then it was back to the DoH. I flagged down a taxi, it stopped. Joyce, Gary, and I got into it, and I stated our destination. "You look as if you are on a mission" said the driver, "we are", we replied, explaining why we were there and about the illness. "Thanks" he said "I have heard of ME but did not know how bad it was but I do now". "More knowledge", I thought, "nice we are doing our job better than the main groups". Back at the DoH, I paid the bill. "Good luck" he said, "you deserve it and thanks for explaining your cause". "Thanks" I said, thinking "one up to the London Cabbies". We rejoined the group in Whitehall and the Sky News team. Two female employees at the DoH asked why we were there. Straight in I went, stating that we were not satisfied at being a political football. I quoted from Professor Hooper's comments on the Norfolk group DVD. He is on record as saying that 2007 would lead to work on a cure. Just lead to more CBT? It had helped 7% but the remaining 93%? My question was: "Did the 7% really have ME or just CFS?". One of them replied that they had had ME but was now recovered, better. I countered with details of the Royal Free, that some who had fallen ill and not returned to work were still ill today, fifty years on.

At one o'clock we went to Downing Street. People were made aware and given more blue ribbons. Joyce was given the honour of knocking on the door this time. The door opened, the presentations were made, then it was back to the DoH. Arrangements were made to get to Parliament to meet the MPs, Labour MPs Yvette Cooper and Glenda Jackson and new Conservative MP Stuart Jackson. We talked with Yvette. She readily accepted the MRC Statement. She said that she would look into encouraging more good quality research proposals into the physical causes of ME, adding that the MRC had millions of pounds to give away to such proposals. I mentioned the peer-reviewing system, adding the question who review the peers, and by what criteria do they judge? One research group had been rejected because they did not have a psychiatrist on their panel. When the current PACE and FINE finish in 2007, we will be nowhere near a cure. This would leave us with the same treatments, achieving nothing. My concerns about the FINE criteria were aired. I had expressed them to those concerned, and no reply had yet been received. Yvette said she would look into this, if a reply was not forthcoming. Lastly, we discussed the early diagnosis issue again. I had case studies of those who had not received an early diagnosis and had got worse. An early diagnosis may let people know what they have got, but may also lead to inappropriate treatment. Closing, I commented that early diagnosis would be better served by a specific diagnostic test, with research into specific medical treatment.

We boarded the bus for home, being disappointed that only a dedicated few turn up. I thought of another dedicated few who fought against the odds, the few that turned the tide in the Battle of Britain. May 12th 2005 saw our dedicated few change attitudes, and hopefully minds, and who knows one day it may be the same few that turn the tide in the Battle for ME. - Trev.