

# breakthrough

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# Breakthrough

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**Publisher:** ME Research UK

ME Research UK funds research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (also known as ME/CFS). It has an international remit, and its principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME/CFS. It also aims to 'energise ME research' by identifying potentially important areas for future biomedical research, producing high-quality professional reviews and reports, presenting research at meetings and conferences, and hosting international conferences.

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# editorial



And so ME Research UK is 10 years old...

A decade might seem a long time, but it is only a twinkle of an eye in the life of a charity. The most perilous years for newborn charities, so they say, are the first five and many fail at this early stage. The ones that survive continue to grow slowly, building up a bedrock of support and increasing in credibility year-on-year for 20, 30 or 40 years. That's why the most successful charities tend to be the longest established.

There's an old saying that the best way to realise just how far you've travelled is to look back; so how far has ME Research UK come in ten years? Well, in that time the charity has provided funding for 29 projects, most over the past 6 years. It's sobering to think that ME Research UK, comparatively small as research charities go, has funded more specific research projects on ME/CFS than any other single organisation in the world outside the American continent.

Without our impetus or funding (alone or with partners) most of these projects would never have taken place. For instance, Prof. Julia Newton's research on autonomic dysfunction at the University of Newcastle would not have begun and flourished into the much larger

programme we see today (see page 6); and the Vascular and Inflammatory Diseases Research Group at the University of Dundee would not have uncovered a range of abnormalities in oxidative stress, apoptosis and arterial stiffness (page 8). Similarly, Prof. Nijs' programme in Belgium on exercise, immunology and its consequences; Dr Jonathan Kerr's investigations of gene snips or comparative genetic signatures; and single investigations, such as the explorations of retrovirus in Swedish patients (page 15) or the experience of pain in Scottish patients (page 4) would not have been instigated or completed.

Yet we have had a wider, more diffuse influence than simply funding specific projects; after all, our mission is to 'energise research' and bring the need for scientific investigation of ME/CFS to the attention of government and professional groups. For example, our chairman, Dr Vance Spence, has given some 58 lectures to a variety of audiences over the decade, and we have been in regular contact with a range of research groups to try to stimulate new research; indeed, the projects we have funded are far fewer than those we have tried to get off the ground, and are only a tiny proportion of those we should like to see commissioned. Also, each year we answer queries from around 400 people by telephone and e-mail in our efforts to provide helpful information and broadcast research findings widely.

The fact that we are one of only a handful of organisations in the entire world funding biomedical research into this illness reminds us of the long journey ahead. In its 10 years ME Research UK has made an enormously valuable contribution; we now need your continued support to take our research agenda forward into the next decade and beyond.

**Dr Neil Abbot**  
**Operations Director**  
**ME Research UK**



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# Experiences of Pain

Pain is a very common symptom in ME/CFS; it tends to be experienced in the muscles and/or joints, but it can often be widespread and changeable in location and intensity. In one survey, quoted in the Chief Medical Officer's report, 79% of patients said that they had severe pain sometimes, much of the time, or all of the time, and between 84 and 94% of patients in formal research studies report some degree of muscle or joint pain. Importantly, 53% of unemployed people surveyed recently by the campaigning charity Action for ME

said that chronic pain was one of the greatest barriers to their obtaining paid employment.

Despite this, there is very little scientific

information about the specific pain characteristics of ME/CFS patients. What kind of pain is it? Where is it localised? What strength is it? To explore such questions, ME Research UK provided part-funding for a PhD studentship, under the supervision of Prof. Lorna Paul and Dr Les Wood (pictured on page 13), at Glasgow Caledonian University. The student, Rebecca Marshall, has now submitted her thesis, and the first scientific paper from her work has just been published in the *Journal of Musculoskeletal Pain*.

For the investigation, 50 people with ME/CFS and painful symptoms were recruited from support groups across Scotland; all had previously been diagnosed by a consultant or general practitioner, and all met the CDC-1994 and Canadian Guideline symptom criteria. No participants had any psychiatric illness or any other serious conditions such as cancer, rheumatoid arthritis or multiple sclerosis (which would have affected their experience of pain).

The investigators visited the patients in their own homes to conduct their interviews, which allowed the

participation of those who were so severely affected that they would not have been able to make a trip to the hospital.

This was particularly important in this study since the researchers wanted to ensure that the findings represented the full spectrum of ME/CFS. Between 10% and 25% of ME/CFS sufferers fall into the "severe" category, so 10 of the 50 patients interviewed by Dr Paul's team were either housebound or bedbound and had been recruited via the national charity, the "25% ME Group" which

caters for severely ill patients.

Overall, the 50 patients had been ill for an average of 12.6 years (range 1.3 to 27.4), and only one was working full time, and two

part-time. A number of tools and questionnaires were used to evaluate participants' experiences of pain, and these consisted of a visual analogue scale, the Margolis Body Chart, the McGill Pain Questionnaire, the Pain Anxiety Symptoms Scale-20 and the Medical Outcome Survey Short Form-36 (see opposite for more detailed descriptions of each of these).

The results revealed that pain is indeed an important symptom of patients with ME/CFS. The most common painful symptom was muscle pain, which was reported by more than two-thirds of patients. The average intensity of pain at the time of the interview was reported to be around 43 out of

## Pain

a maximum of 100 mm on the visual analogue scale, while the average intensity over the previous 24 hours was higher at around 58 mm. The investigators suggest that this latter value may be a more accurate reflection of patients' experiences, particularly if pain fluctuates. Significantly, ME/CFS patients reported worse pain than did patients with rheumatoid arthritis or multiple sclerosis in previous studies, both conditions in which pain is recognised as a major symptom.

Patients used words such as "throbbing", "aching", "tender", "gnawing" and "burning" to describe the pain they experienced, while those with more severe illness also used "exhausting" and "nagging". In fact, as the chart opposite shows, only the severe patients chose the word "gruelling" while



none chose the less emotive words “tight” or “annoying” — indicating more severe pain, and intensity, in the most severely affected group.

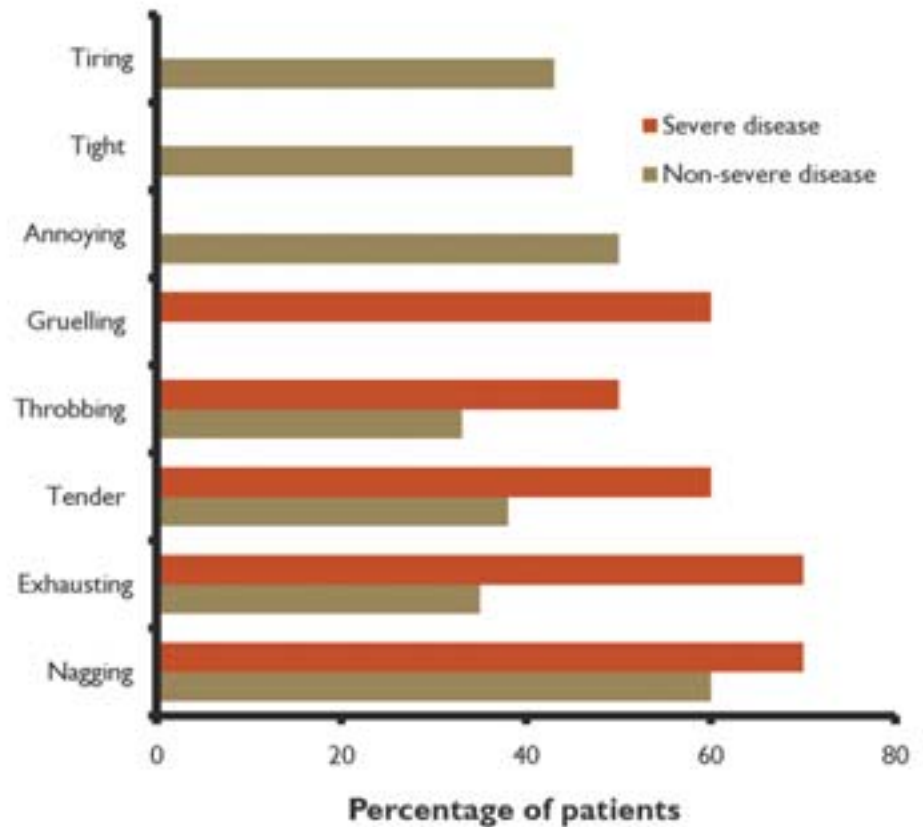
These descriptions may give clues as to the mechanisms causing pain in ME/CFS; in particular, “burning” pain is often associated with neuropathic conditions in which the nerves have been damaged. Also, they may help in assessing any change in the quality of pain over time, such as after treatment, as Dr Paul’s group suggests. Despite this burden of pain, most participants described their mood as generally positive, although those with more intense pain tended to describe a lower mood.

The most common locations of pain were the cervical spine (in 66% of patients), the anterior thighs (44 to 46%), the lumbar spine (42%) and the posterior calves (38%), and most participants had pain in more than one location. Nearly a third of patients said they experienced their most severe pain in the area of the cervical spine/upper trapezius, while 20% reported the scapular/upper thoracic area and another 20% reported the right lumbar spine as the most painful regions. Twenty-eight participants said they experienced the worst pain in the morning, while it was the afternoon for four individuals, the evening for ten and the night for eight.

The results of the Pain Anxiety Symptoms questionnaire suggest that the study participants were not overly anxious or fearful because of their pain, although the most severely affected were more susceptible. When considering quality of life, Dr Paul’s findings were similar to those of Dr Gwen Kennedy’s study from 2004 (published in the *Annals of Epidemiology*). Patients tended to have reduced physical functioning and vitality (but not emotional or mental health), and again this was more pronounced in those with more severe illness.

This is the first major study to document and categorise the pain experienced by people with ME/CFS, and to provide sound, objective, scientific support to their anecdotal and clinical reports of painful symptoms. As the authors say, “*This study has emphasised that the problem of chronic pain... needs to be treated as seriously as the pain experienced in other conditions such as rheumatoid arthritis and multiple sclerosis.*”

## Descriptions of pain used by ME/CFS patients



### Visual analogue scale

Participants are asked to indicate their current pain intensity on a visual scale from 0 mm, representing “no pain”, to 100 mm, representing “most pain ever experienced”.

### Margolis Body chart

Participants use a diagram of the human body to indicate the areas in which they experience the most pain. This is then matched to a chart which divides the body into 45 sections, in order to identify the locations of most pain.

### McGill Pain questionnaire

Participants are asked to describe their pain using words from a standard list of 78, grouped into 20 subcategories. Numerical values are assigned to each word, and a Pain Rating Index is calculated as the total of the values for each word chosen. This provides a measurement of the pain itself (sensory component), as well as unpleasant feelings and emotions (affective component), and how it is judged by the sufferer (evaluative component).

### Pain Anxiety symptoms scale-20

Participants are asked to score their experience of 20 psychological aspects of pain, such as anxiety, fearful thinking, feelings of wanting to escape or avoid a situation, and physiological responses. Each item is scored from 0 (never) to 5 (always), and the total is calculated out of a maximum of 100.

### Medical outcome survey short Form-36

A questionnaire consisting of 36 questions examining physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role and mental health. The participant’s answers to each question are translated into a total score from 0, representing poor health, to 100, representing good health.

# Abnormalities in Muscle

The autonomic nervous system has a range of important functions, so the consequences can be severe when it goes wrong. Since ME/CFS patients experience symptoms such as dizziness, altered vision, nausea and fatigue when they are standing, particularly when they are standing still, the possibility exists that the autonomic nervous system could be at fault.

Since 2006, with the financial help of ME Research UK, Professors Julia Newton and David Jones (pictured) of the School of Clinical Medical Sciences, University of Newcastle, have examined a large group of patients using a battery of tests of autonomic function, including heart rate and blood pressure. In a series of fascinating scientific papers, they have reported finding autonomic dysfunction in three-quarters of ME/CFS patients, a most unexpected result; they have shown that the heart rate response to standing is abnormal in a significant proportion of patients; and they have confirmed that blood pressure is lower, and blood pressure regulation abnormal, in this clinical group compared with healthy people.

The autonomic nervous system also plays a part in regulating events in exercising muscle, however, and the researchers hypothesised that it might be involved in the exercise-induced symptoms so characteristic of ME/CFS. To examine this, they enlisted the help of phosphorus magnetic resonance spectroscopy (MRS), a marvelous tool which allows assessment of acid (pH) handling inside the muscle where the problems might lie.

Sixteen ME/CFS patients and healthy controls matched for age and sex underwent MRS to examine acid handling in their



**These findings point to a significant impairment of proton excretion following exercise**

soleus and gastrocnemius muscles during exercise, which involved raising and lowering the foot under very controlled conditions. Measures of autonomic function were also assessed.

Prof. Jones' and Newton's results have just been published in the *Journal of Internal Medicine* (2010).

Compared with normal controls, the patients' proton efflux (a measure of acid handling) was reduced immediately after exercise (see the figure opposite), while their time taken to reach maximum proton efflux was significantly prolonged, and the magnitude of maximum proton efflux was reduced compared with the controls. Taken together, these findings point to a significant impairment of proton excretion in the recovery phase following exercise — in simple terms, ME/CFS patients recovered substantially more slowly than controls.

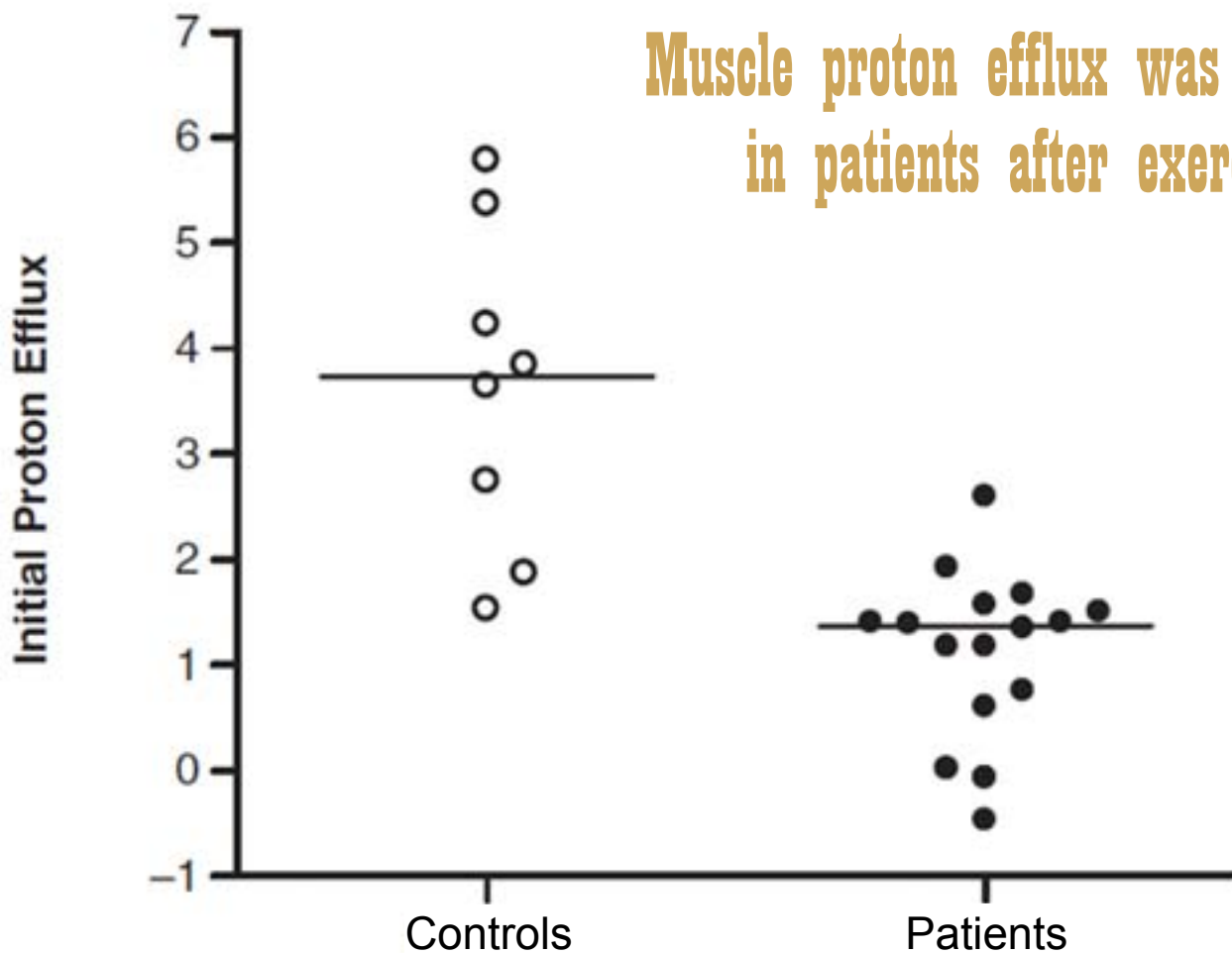
Could simple deconditioning be the cause? Probably not, since both maximum voluntary contraction measurements and muscle volume were similar in patients and in the inactive controls. Rather, the researchers think it more likely that impaired acid handling could be one of the mechanisms through which autonomic abnormalities act to produce post-exercise symptoms and fatigue, given the role played by the autonomic nervous system in the regulation of acid transporter pathways and vascular flow in muscle.

Despite the key role of post-exercise symptoms in the illness, there has actually been very little scientific investigation into muscle physiology during exercise in ME/CFS — a fact that makes these novel findings so important. Based on these results, ME Research UK has now organised funding for the next step: an examination of the function of an energy-generating enzyme which might be under-performing in people with ME/CFS (see opposite).



**Prof. Julia Newton and Prof. David Jones**

## Muscle proton efflux was reduced in patients after exercise



## Focusing on muscle: next steps in Newcastle

In the historical literature, the hallmark of myalgic encephalomyelitis (ME) has been marked muscle fatigability often in response to minor degrees of exercise. Muscle cramps, twitching and extreme muscle tenderness were also common findings. And today, patients diagnosed with ME/CFS frequently highlight the importance of peripheral “fatigue”, such as impairment of muscle power, in their experience of illness. So it makes sense for researchers to focus on muscle.

Given their results published this year in the *Journal of Internal Medicine*, the next step for Prof. Jones and his colleagues is to see whether a problem with muscle “bioenergetics” might be at the root of the slower recovery from exercise seen in ME/CFS patients. For instance, it might be that acid build-up during exercise is the result of an under-performing energy-generating enzyme within the mitochondria (the “batteries of the cell”). To investigate this, the researchers will undertake a range of in vitro studies, all based on primary assay and culture of muscle cells (myocytes) in the laboratory, using cells harvested from ME/CFS patients and from matched normal and chronic disease controls.

The first phase of the investigative strategy has already been funded by the Northern Clinical Network in Newcastle, and involves an examination of the function of ME/CFS patients’ cultured muscle cells; the muscle biopsies taken during this phase represent a unique opportunity to study the pathways of metabolism within muscle, exploring the expression of the key energy-generating enzymes and cell proteins which help to control acid build up within the cell.

The second phase has been funded by ME Research UK and involves array studies to look at metabolic gene expression in muscle. The aim is to show whether cultured muscle cells from patients with ME/CFS have altered gene expression, and whether the response of gene expression to “exercise in vitro” is impaired in patients’ muscle cultures.

The exciting thing is that this series of interlinked studies brings together investigators from diverse academic backgrounds (muscle energetics, muscle cell culture and nanotechnology development), all members of the Institute of Cellular Medicine within Newcastle University, and all applying their skills to the illness ME/CFS for the first time.

# Biochemical abnormalities in children with ME/CFS



There is a particular poignancy to illness in youngsters; the transformation of a bright, active child into one who is unable to go to school or play with friends is something that touches us all.

Estimates of the numbers of children affected by ME/CFS vary, but with prevalence figures of 60 to 70 cases per 100,000, it is likely that around 9,000 people under the age of 16 in the UK have this diagnosis. As the report to the Chief Medical Officer in 2002 made clear, this illness “represents a substantial problem in the young” and “potentially threatens physical, emotional, and intellectual development of children and young people, and can disrupt education and social and family life, at a particularly vulnerable time of life”.

In a previous issue of *Breakthrough* (issue 11, Spring 2010), we reported the results of a study on the quality of life of children with ME/CFS, recently published in *Pediatrics* by Dr Gwen Kennedy of the Vascular and Inflammatory Diseases Research Unit in the University of Dundee. In parallel with this work, Dr Kennedy and her colleague Dr Faisal Khan have been investigating biochemical and vascular abnormalities in children with the disease, and their results have just been published in the US journal *Archives of Pediatrics and Adolescent Medicine*. Like the previous study, this work was supported financially by ME Research UK, The Young ME Sufferers (Tymes) Trust, Search ME and Tenovus Scotland.

The Dundee group has previously reported a number of biochemical and

vascular abnormalities in adults with ME/CFS. These mainly involve the immune and cardiovascular systems, and include an increase in the programmed death (apoptosis) of white blood cells, raised levels of oxidative stress which can damage blood vessels and other organs, increased markers of inflammation, and abnormalities in blood vessel function. All of these are potentially associated with a future risk for cardiovascular problems such as heart disease and stroke.

Drs Kennedy and Khan wanted to investigate whether these abnormalities were also present in children with ME/CFS, given the potential long-term consequences. Risk factors such as high

cholesterol and increased blood pressure, which are usually associated with adult diseases, have also been found in children. These progress into adulthood as hypercholesterolaemia and hypertension, so it is important that risks are identified as early in life as possible.

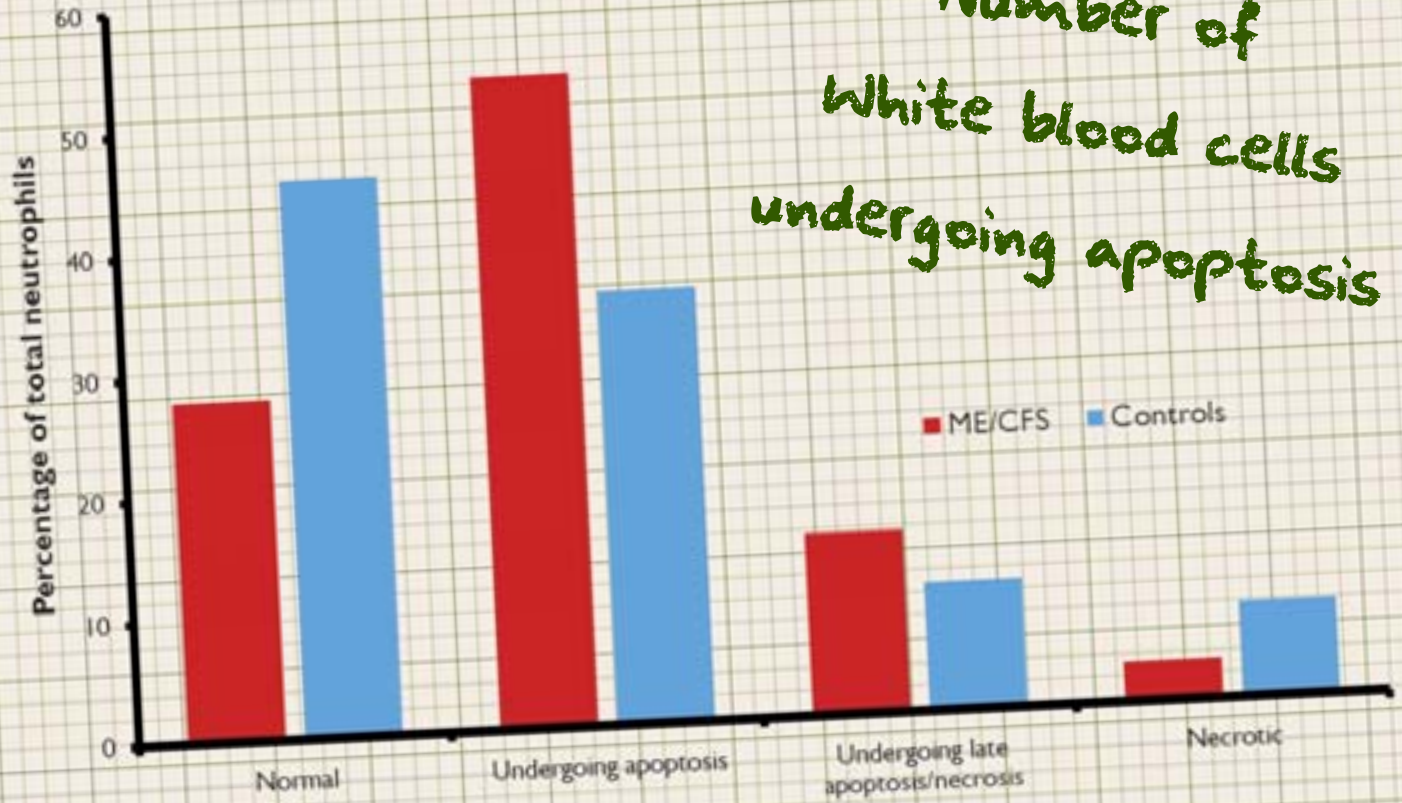
Twenty-five children with ME/CFS (all between the ages of 10 and 18 years) and 23 healthy children matched for age, gender and stage of puberty were recruited from throughout the UK. The diagnosis of ME/CFS had been made according to a revised version of the CDC-1994 case definition, and was confirmed by the researchers from a clinical examination.



Dr Gwen Kennedy



## Number of White blood cells undergoing apoptosis



A blood sample was taken from each child (using an anaesthetic cream to minimise their discomfort), and this was then subjected to a battery of tests in Dr Kennedy's laboratory (see the box overleaf). The child's blood pressure was measured, and then the pulse at their wrist was detected using a special pen-like probe applied lightly to the skin. This records the fluctuations in pressure as each pulse travels along the artery, and is exactly what you feel with your finger when you take your own pulse. This recording of the pulse is then analysed on a computer to give information on how flexible the artery is, which gives an indication of its health and function.

Overall, compared with healthy control children, the young people with ME/CFS had:

1. Higher levels of oxidative stress, manifested as elevated levels of isoprostanes.
2. Reduced levels of vitamins C and E.
3. A greater percentage of white blood cells undergoing apoptosis (see the graph above).
4. A trend towards increased arterial stiffness, although this was not statistically significant.

As Dr Kennedy points out, the increased oxidative stress may be due to a deficiency of antioxidants in the diet (such as vitamins C and E, found to be reduced in this study). However, she feels it is more likely to have been caused by white blood cells releasing an excessive amount of highly reactive free radicals, possibly from exercising muscle. This would tie in with the finding of increased white cell apoptosis, and Dr Kennedy has previously reported increased oxidative stress following exercise in adults with ME/CFS. She does emphasise, however, that more studies, perhaps including an assessment of diet, are needed to determine this mechanism.

The increased apoptosis (or programmed cell death) may be caused by a number of factors, including a persistent viral infection or toxic agent, or an abnormal immunological response. This

finding is particularly intriguing given that many patients, including most children in this study, report that their disease started following a viral infection of some kind.

At present however, there is insufficient evidence to make a causal link between infection and increased apoptosis, though the finding is tantalising.

Although there were no other statistically significant changes in the children with ME/CFS, there was a clustering of markers such as arterial stiffness and cholesterol that showed small changes which may indicate the

possibility of future cardiovascular risk. This type of clustering has been shown before in healthy children and in young people with diabetes. Although it should be stressed that children with ME/CFS are at no immediate risk of developing cardiovascular problems, we might expect these changes to become greater (closer

**Children with ME/CFS have an abnormality in the behaviour of their immune cells**



to the adult pattern) as the children grow older and have been ill for longer.

Dr Kennedy and her team conclude their report by saying that the findings show that many children with ME/CFS “have an underlying, detectable abnormality in the behaviour of their immune cells, consistent with an activated inflammatory process”, and provide evidence of “a persistent or reactivating viral infection triggering apoptosis of white blood cells with an increased production of free radicals”.

It is important that these abnormalities have now been recognised in children with ME/CFS. To date, aside from symptomatic treatments, no specific therapy is available for children or adults with ME/CFS, so there is an urgent need for intervention trials. Based on these and other biomedical findings in the disease, putative therapies could perhaps include both pharmacological and non-pharmacological strategies (to treat dysautonomia, for example), or antioxidant or antiviral interventions.

## Biochemical measurements

### Oxidative stress

Oxidative stress is damage caused by highly reactive molecules called free radicals. They are normally kept under control by natural processes which remove them from the circulation, but when an imbalance occurs they can be left to cause damage unchecked. In particular, free radicals can change our normal “good cholesterol” into something more harmful, leading to heart and circulation problems. This “bad cholesterol” is known as **oxidised low density lipoprotein**. The reaction of free radicals with essential fatty acids (which are important substances obtained from the diet) produces compounds called **isoprostanes**, which act as another marker of oxidative stress. Other signs of oxidative stress include low levels of **vitamin C** and **vitamin E**.

### Inflammation

Inflammation is a complex set of immunological and vascular processes which occur in response to injury or infection. Although it is a vital part of our body’s defence mechanism, prolonged inflammation can be harmful to otherwise healthy tissue, and causes diseases such as rheumatoid arthritis. In particular, it can cause damage to blood vessels leading to cardiovascular disease. **C-reactive protein** is found in the blood and its levels rise in response to inflammation, making it a useful marker.

### Apoptosis

Apoptosis is the programmed destruction of unwanted cells in the body. It is an important process removing cells that have reached the end of their natural life, as well as controlling infections. Apoptosis is carried out by white blood cells called neutrophils, which are part of the immune system. Increased apoptosis can be a sign of abnormalities in the immune system, and may be caused by a persistent viral infection or quicker-than-normal turnover of neutrophils. Apoptosis can be measured by looking at the expression of the protein **annexin V** and other substances on the surface of neutrophils. This gives an indication of what proportion of these cells are healthy, dead because of external factors, or dead because of apoptosis.

## Financial support for this project

### The Tymes Trust

The Young ME Sufferers (Tymes) Trust is the longest-established UK service for children and young people with ME and their families. It runs an advice line, provides access to ME experts for doctors, teachers and social workers, and produces a magazine for children, families and professionals. The Trust played a major role in producing the children’s section of the Department of Health Report on CFS/ME (2002). See their website [www.tymestrust.org](http://www.tymestrust.org) for details and free publications.

### Search ME

Search ME, based at Rosyth in Fife, was founded in 2002. Its aims are to improve the lives of people with ME and to provide them with a voice on the Cross Party Group for ME in the Scottish Parliament. The charity has raised the bulk of its donations through organising rock and pop concerts. Search ME became an early supporter of the work at the University of Dundee and helped fund the research carried out there. Further information can be found on their website [www.search-me.org.uk](http://www.search-me.org.uk).

### Tenovus Scotland

Tenovus has been supporting innovative medical research within Scottish Universities and Teaching Hospitals for over 40 years. It raises funds through private donations, Trusts, legacies and fundraising events, and its principal aim is to assist young research staff with small grants to get their research programmes underway. Find out more at their website [www.tenovus-scotland.org.uk](http://www.tenovus-scotland.org.uk).

# ME Research UK

## The first 10 years



The people who gathered for lunch at Murrayshall House Hotel in rural Perthshire on 3rd October 2010 were there at their own expense to celebrate the 10th Anniversary of ME Research UK (the photo below shows staff, volunteers and family members).

The charity was founded in 2000 by Dr Vance Spence, Robert McRae and Roger Jefcoate CBE (who became founding patron), all of whom realised something had to be done to promote and fund research into ME/CFS. As Vance

says, *“Good scientific research into ME is vital, but looking around we saw that basic biomedical research was grossly underfunded. If money and resources could be found, then the tectonic plates might start to move. We were also concerned that the research picture was heavily skewed towards psychiatry and psychology, an odd business since Bob and I had a physical illness and had no psychological problems.”*

With the support of our patrons The Countess of Mar and Dr Gordon Parish, the organisation has grown in size and

respect over the decade, punching above its weight in a variety of spheres.

The trustees have bold plans for the future, based on the small, committed team of core staff, an advisory panel of professional scientists, and a group of trusted volunteers who help the charity to run efficiently. From this strong start, the whole team are committed to establishing ME Research UK as a major force for change that will make a real, long-term difference to the lives and prospects of people with the illness.



# A decade of research

Over the past 10 years we have funded the work of a number of scientists in the UK and overseas, whose research covers several different areas of interest.

Funding was provided for 29 specific investigations on ME/CFS patients (some of which are listed on the right), and we are particularly grateful to some of the ME organisations which have provided larger donations to help us fund specific projects.

Our priority has always been to support innovative clinical and biomedical studies, based in established research institutions, investigating the causes of ME/CFS and the effectiveness of potential treatments. All our grants are competitive and are subject to peer review. Fuller details of these and other projects, including the key findings published in scientific papers, can be found at the research section of our website.

## An example of consistent funding

Unravelling the scientific basis of ME/CFS, or the collection of diseases currently given that label, is no simple matter. Funding one-off investigations is useful since these can provide pilot data for subsequent grant applications, or spark off interest in other researchers.

But in modern science, real breakthroughs come at the end of a programme of painstaking work by a specialist group of researchers. One of the few examples of such a programme on ME/CFS, anywhere in the world, is the work at the Vascular Diseases Research Unit, University of Dundee.

This group has received a number of grants from ME Research UK in the past 10 years. In a step-by-step progression involving both adults and young people with the illness, the group has uncovered a number of abnormalities.

- 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.
- Increased cardiovascular risk factors with arterial stiffness in patients.
- Biochemical anomalies in children mirroring those found in adults with the illness.

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 science fields, so that a 'critical mass' of investigators can produce a 'critical mass' of biomedical data.

- Unusual sensitivity of blood flow to acetylcholine (a neurotransmitter).



**Dr Gwen Kennedy**



**Dr Jo Nijs**



**Dr Ellie Stein**



**Dr Jonathan Kerr**



**Delegates at the 2008 New Horizons Conference**

# Projects funded by ME Research UK

## **Exercise, pain, and the immune and sensory systems**

Dr Jo Nijs, Vrije Universiteit Brussel, Brussels, Belgium

## **Muscle bioenergetic abnormalities**

Prof. David Jones, Institute of Cellular Medicine, University of Newcastle

## **XMRV in Swedish patients**

Prof. Jonas Blomberg and Prof. Carl-Gerhard Gottfries

Uppsala University Hospital, Sweden

*(with co-funding from the Irish ME Trust)*

## **Vitamin D supplementation and cardiovascular disease risk**

Dr Faisal Khan, Institute of Cardiovascular Research, University of Dundee

## **Autonomic nervous system dysfunction — a clinical study**

Prof. Julia Newton, School of Clinical Medical Sciences, University of Newcastle

*(with cofunding from the Irish ME Trust and the John Richardson Research Group)*

## **Interleukin-6 and its receptors**

Prof. Myra Nimmo, University of Strathclyde, Glasgow

## **Biochemical and blood flow aspects in children**

Dr Gwen Kennedy, University of Dundee

*(with cofunding from The Young ME Sufferers Trust and Search ME)*

## **Evaluation of pain and therapeutic interventions**

Dr Lorna Paul and Dr Les Wood, Glasgow Caledonian University

## **Gene expression studies**

Dr J Kerr, St George's Hospital, University of London

*(co-funded by the Irish ME Trust)*

## **Non-invasive neuroimaging of the brain**

Prof. BK Puri, Imperial College London

*(with co-funding from ME Solutions and the MRC Clinical Sciences Centre, Imperial College)*

## **Exercise tolerance and post-exertional symptoms**

Prof. Brian MacIntosh and Dr Eleanor Stein, University of Calgary, Alberta, Canada

## **Chronic inflammation and apoptosis (programme)**

Prof. J Belch, Vascular Diseases Research Unit, University of Dundee

## **Differential gene expression**

Prof. J Gow, University Department of Neurology, Glasgow

## **Novel mechanisms of fatigue in ME/CFS**

Dr P Ansley, Northumbria University, Newcastle upon Tyne

## **Effects of muscle fatigue on H-reflex excitability**

Dr Les Wood, Glasgow Caledonian University



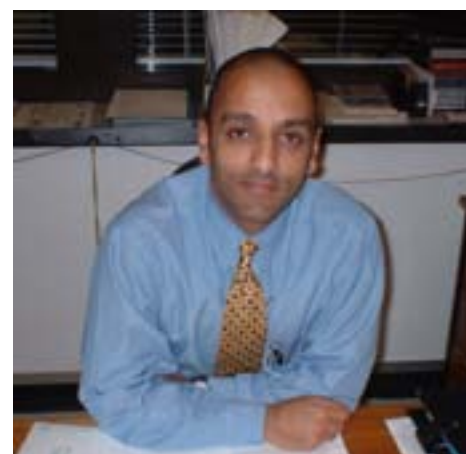
**Dr Julia Newton**



**Prof. Jonas Blomberg**



**Dr Les Wood and Dr Lorna Paul**



**Dr Faisal Khan**

# Raising awareness The first 10 years

ME Research UK's mission to "Energise ME Research" involves raising awareness of the need for biomedical research to a variety of audiences, hosting conferences and meetings, and providing high quality information on all aspects of the illness: from summarising and appraising scientific literature on ME/CFS to informing the policy agenda. Here are some of our key achievements.

## Scientific meetings

We have hosted two New Horizons International Research Conferences (Edinburgh 2007 and Cambridge 2008); a Research Colloquium (2007); and a Research Workshop (2005).



## DVDs produced

A DVD lecture by Dr Vance Spence on research issues and challenges was made, and 3,000 copies distributed. We also produced films of our conferences.

## Books and key articles

"Shattered — Life with ME" (Thorsons) by Dr Lynn Michell, an early trustee of the charity, was produced and distributed. And a plethora of specialist articles have been written for the magazines of local and national ME organisations (see the information section of our website).

## XPG at Scottish Parliament

We provided the impetus and initial funding for the formation of a Cross Party Group on ME at the Scottish Parliament.

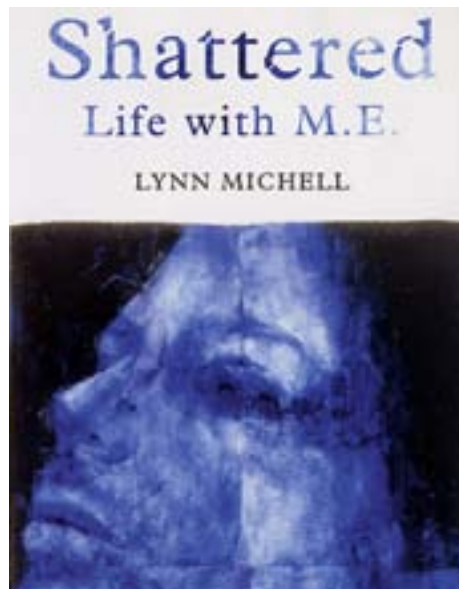


## Royal visit

In 2009, we were honoured with a visit from His Royal Highness The Prince Edward, who met the team and was introduced to our work.

## Talks and presentations

Dr Vance Spence gave some 58 public talks on ME/CFS research and related issues in ten years, at venues ranging from Sheffield and Southampton to Dumfries and Dublin.



## Informing policy

Formal representations to official bodies have included: Royal Society of Medicine (2009); National Institute for Clinical Excellence (2006–7); Gibson Westminster Parliamentary Inquiry (2006); Royal College of Paediatrics and Child Health guidelines (2006); and Scottish Parliament (2001 and 2005).



## Breakthrough magazine

We have developed Breakthrough into a full-colour bi-annual magazine featuring research and comment, with a readership of almost 7,000.

## Website

Our website, which also contains our research database, has become a source of information for researchers, health care professionals and people with the illness across the world.



# XMRV: the plot thickens

In October 2009, a scientific paper in the prestigious journal *Science* reported the discovery of a potential retroviral link to ME/CFS, which is estimated to affect some 17 million people worldwide.

The consortium of researchers, including the Whittmore Peterson Institute (WPI) located at the University of Nevada, USA, had found that DNA from xenotropic murine leukaemia virus-related virus (XMRV) could be detected in the peripheral blood mononuclear cells of 67% of ME/CFS patients compared with only 3.7% in controls, and that XMRV proteins were being expressed in blood cells from ME/CFS patients at very high levels compared with controls.

Since the presence of infectious XMRV in white blood cells of patients could account for some of the known features of this chronic illness (e.g., neurological symptoms and immune dysfunction with inflammatory cytokine upregulation), the finding was tantalisingly appropriate. However, scientific results must be confirmed by others, and the crucial first step is for other independent laboratories across the world to look for XMRV infection in their own local populations. So ME Research UK (along with the Irish ME Trust) quickly provided funding for researchers to test Swedish ME/CFS patients (see the Spring 2010 issue of *Breakthrough*).

In the ten months following the initial report, four other studies have been published, all “negative” for the presence of the virus in English, Scottish, Dutch and American patients. At first glance, these negative reports from four different research groups across the globe, each with a track record in virology, is a serious blow to hopes of XMRV involvement in ME/CFS.

However, the situation is more complex, and the past few months have seen an intense discussion of intricate methodological issues. As Dr Robert



Silverman, the discoverer of the XMRV virus, makes clear in an excellent review (*Nature Reviews Urology*, July 2010), there might be several reasons — apart from plain contamination, which is unlikely — for radical differences between studies.

First, there could be geographical differences in the distribution of XMRV, as is the case with another human retrovirus, HTLV-I. Next, sequence variations in XMRV, and the existence of divergent or related viruses, is possible, and these could easily be missed by many of the methods, in particular protein chain reaction (PCR).

Also, the absence of standardised, highly sensitive methods for the detection of XMRV, coupled with a lack of widely available, positive control human samples, might be contributing to the different results obtained between studies. This last point is important, particularly if XMRV is indeed hard to detect by the conventional PCR methods used in the four negative papers; a recent scientific article (*Virulence*, Sep/Oct 2010) has proposed four additional blood-based lab assays for more sensitive detection of XMRV.

Then, in a dramatic twist to the story, Dr Harvey Alter of the National Institutes of Health published a report in *Proceedings of the National Academy of Sciences* (23rd August 2010). His team were examining

long-stored samples from 37 CFS patients for traces of the XMRV “gag gene”. But instead of finding XMRV itself, they uncovered a more diverse group of closely related viruses; startlingly, these were present in 86.5% of the patients but only 6.8% of the control samples.

The researchers claim that the diverse viral sequences identified closely resembled the polytropic mouse viruses (those infecting a range of hosts including mice), which is why they adopted the term “MLV-related virus” (see the box below). However, Dr Alter pointed out that his work supports the original report in *Science* in 2009 since XMRV is a

subset of MLVs, although his team did not precisely replicate the work in the original study.

Whether or not MLV-like viruses play a critical role in ME/CFS, the scientific twists and turns of the past year have been absorbing and compelling, and more are yet to come.

## What are MLVs?

Murine leukaemia viruses (MLVs) are gammaretroviruses capable of causing mouse (murine) cancer.

There are many types of MLVs, most used in cancer research (for example, specific genes can be delivered to target cells by MLV-derived particles).

XMRV is part of the MLV “family”, but an unusual one because it can infect other non-mouse species — hence its name “xenotropic”.

Dr Alter reported evidence for three different variants of MLV in ME/CFS patients, though one predominated, infecting 86% of patients.

# Recent research from around the world



## CHICAGO

### Indomitable spirit

While recovery from ME/CFS is a real possibility, particularly in the young, many people still remain chronically ill for a number of years coping as best they can. Healthcare professionals recognise a number of different “strategies” for coping with chronic illness, ranging from self distraction or denial or self-blame to humour or religious faith. So, which strategies are most often used by ME/CFS patients, and does length of illness make any difference to how they cope?

Researchers from DePaul University, Chicago (writing in *Psychological Reports*) compared coping strategies between ambulatory adult patients with a longer (more than 2 years) or shorter (2 years or less) duration of illness. Patients’ levels of illness and symptoms were assessed, and the Brief COPE inventory was used to identify their ways of coping.

Interestingly, there were no differences in physical impairment or symptom severity between the two groups. But people with a longer duration of illness were more likely to use

strategies such as active coping (e.g., “taking action to try to make the situation better”), positive reframing (“looking for something good in what is happening”), planning (“thinking hard about what steps to take”) and acceptance. And they were less likely to use behavioural disengagement (such as “giving up the attempt to cope”) than people ill for a shorter time.

The key finding that patients show improvements in coping over time, regardless of their physical function or symptoms, illustrates one thing: the indomitable power of the human spirit in coming to terms with a dreadful clinical and social situation.

## BATH

### Subgroups in children

There are some 13 million people in the UK under the age of 16, and we’re told that around 9,000 (0.07%) of them have a diagnosis of ME/CFS. But what does that mean? Do they all have the same underlying disease or might there be a

collection of different illnesses in this diagnostic black box?

To investigate this, the Bath specialist paediatric service which covers the south-west of England decided to review its data on children assessed between 2005 and 2008. The team employed factor analysis, a statistical technique that uses correlations between symptoms to determine individual “factors” that might hypothetically correspond to pathological disease processes, and might identify clinically differentiable subgroups (“phenotypes”) of children. Analyses were performed on the symptoms reported at initial assessment by 333 children and young people (average length of illness 17 months, 40% attending school), and regression analyses included variables such as sex, age, length of illness, anxiety and markers of severity (fatigue, physical function, pain and school attendance).

The scientific report (published in *Archives of Disease in Childhood*) identified three different clinical “phenotypes”, described under the broad headings of musculoskeletal, migraine and sore throat. The musculoskeletal subtype was associated with muscle and joint pain, and hypersensitivity to touch, and was more strongly associated with fatigue than the others. The migraine subtype was associated with noise and light hypersensitivity, headaches, nausea, abdominal pain and dizziness, and it also had the strongest association with lower physical function and worse pain than the other phenotypes. The sore throat subtype was associated with sore throat and tender lymph nodes. This appeared to be the least severely affected group, and was associated with female gender but not with fatigue or pain. Interestingly, neither age, length of illness or symptoms of depression seemed to affect phenotype classification.

While factor analysis cannot prove the existence of separate illnesses sheltering under the umbrella term “ME/CFS”, the finding that three phenotypes can be clearly differentiated from each other in children with the diagnosis is certainly suggestive.



## MIAMI

### Natural born killers

Ask any person with ME/CFS what advance in research they would most like to see, and surely a diagnostic test or marker for the disease would come near the top of the list. Genetics might appear to provide the greatest hope in achieving this goal, but there are other options, as a team of researchers from the University of Miami have recently demonstrated.

Their work (published in *PLoS One*) has focused on two potential markers that are thought to be involved in the development of ME/CFS. First, natural killer cells, which are a type of white blood cell responsible for killing other cells; they are important in the body's immune defence against tumours and viral infections, but their function appears to be deficient in ME/CFS. Second, dipeptidyl peptidase IV (also known as CD26), which is an enzyme also involved in immune regulation and programmed cell death,

and which has previously been found to be a marker for various types of cancer. The levels of this enzyme on lymphocytes (white blood cells) has also been shown to be increased in people with ME/CFS.

The Miami study found that the cytotoxic function of natural killer cells was significantly lower in 176 ME/CFS patients than in 230 healthy controls. Also, the proportion of lymphocytes positive for CD26 was higher in the patients than in the controls, while the levels of CD26 expressed on T cells and natural killer cells and in the blood was lower. Taken together, these observations are consistent with the idea that infection is involved in the initiation and/or persistence of ME/CFS.

Could natural killer cells' cytotoxicity and CD26 expression, or a combination, become useful as objective markers for diagnosis or treatment targeting? Well, as you read this sentence, the researchers are engaged in the next phases of their work, looking at how these markers change throughout the illness, to answer that very question.

## UTAH

### Gene expression during exercise

The cardinal symptom of ME is profound, post-exertional loss of muscle power associated with muscle pain, tenderness and swelling, and "post-exertional" symptoms are still key to diagnosis. Even the imperfect NICE Clinical Guideline of 2007 insists that post-exertional malaise should be present. Experimental studies of the effects of exercise in patients are therefore vital, and a recent report (published in the *Journal of Pain*) has examined gene expression 8, 24 and 48 hours after a 25-minute bout of whole-body exercise involving a combined arm-leg cycle ergometer.

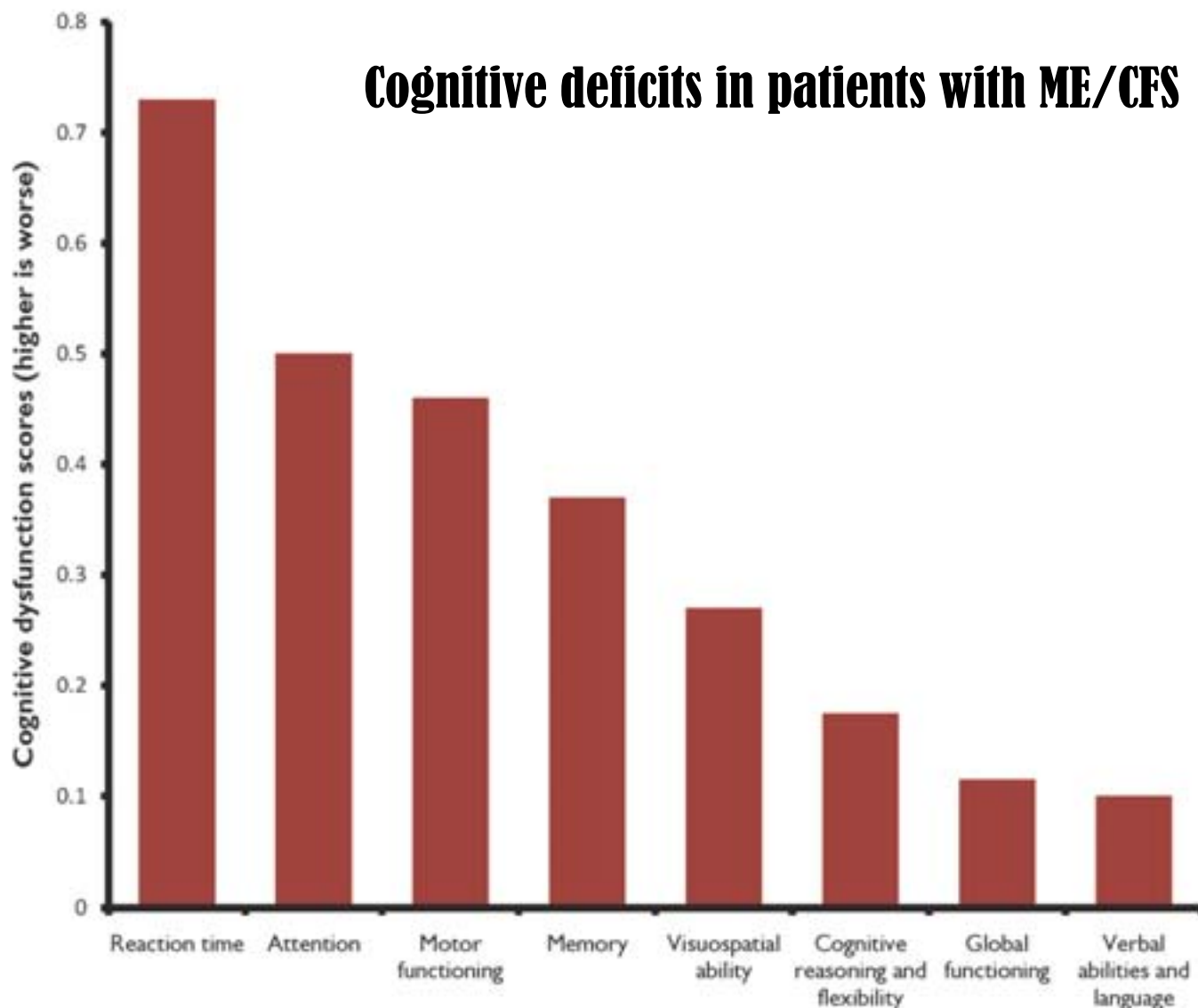
ME/CFS patients, but not healthy controls, reported increased physical fatigue up to 48 hours after the exercise bout, and only this group showed significantly increased levels of pain and increased mental fatigue up to 48 hours. But the gene expression results were the most interesting. With this moderate exercise task, the 16 healthy control subjects exhibited no significant increases in expression of any of the genes, whereas the 19 ME/CFS patients showed increases in the expression of a variety of genes.

Overall, the patients showed greater increases than healthy people in genes that can detect increases in muscle-produced metabolites (ASIC3, P2X4 and P2X5), genes that are essential for sympathetic nervous system processes (adrenergic  $\beta$ -2A,  $\beta$ -1 and  $\beta$ -2, as well as COMT), and immune function genes (IL10 and TLR4) — increases that were observed to last from 30 minutes to 48 hours. In the subgroup of ME/CFS patients who also had fibromyalgia, these increases were highly correlated with symptoms of physical fatigue, mental fatigue and pain.

Given that approximately 90% of the ME/CFS patients could be distinguished from healthy controls using four of the genes measured (P2X4,  $\beta$ -1,  $\beta$ -2 and IL10), it may be that alterations in gene expression from circulating white blood cells after exercise could come to be used as objective markers for the illness, although much more work would be required to establish this with certainty.



# Cognitive deficits in patients with ME/CFS



## AUSTRALIA

### Memory and attention problems

Neurocognitive problems are one of the most frequent and disabling symptoms associated with ME/CFS. In one investigation, 89% of patients reported memory/concentration problems, while in another large study memory/attention deficit problems were reported by approximately 90% of 2,073 consecutive patients. Crucially, patients often report that their cognitive problems can be made worse by physical or mental exertion. But do such self-reported anecdotes about cognitive symptoms also show up as measurable deficits on objective cognitive testing in a clinical setting?

Meta-analysis is a method of combining results from a range of studies to obtain an overall estimate of the “true”

effect of a treatment. Researchers at the University of Adelaide, South Australia have just published (in *Psychological Medicine*) a meta-analysis of all relevant clinical trials examining cognitive functioning in people with ME/CFS, with the aim of identifying the pattern and magnitude of these deficits. Overall, they found a very mixed bag of 50 studies (made up of 1,577 patients and 1,487 controls) published between 1988 and 2008 from which, nevertheless, a clear and very revealing pattern emerged on detailed examination.

The most significant cognitive deficits (see the chart above) were found in “attention” (encompassing attention span and working memory), “memory” (examined from verbal and visual memory tests, mostly memory for word lists) and reaction time (assessed as responses to both simple and complex choice stimuli). These results were consistent with the memory and concentration problems that patients themselves complain about. In

contrast, there were no apparent deficits on tests of “fine motor speed”, “vocabulary”, “reasoning” or “global functioning”, suggesting that the “higher order” cognitive abilities such as language, reasoning and intelligence remain unimpaired. Importantly, most studies that examined the impact of self-reported depression on cognitive functioning failed to find a relationship, indicating that depression was not responsible for most cognitive impairments.

The range of these studies and the clarity of the findings leave no doubt that people with ME/CFS have moderate to large impairments in simple and complex information processing speed, and in tasks requiring working memory over a sustained period of time. As the authors point out, the deficits in performance are around 0.5 to 1.0 standard deviations below that of healthy people, a fact which explains the significant impact cognitive problems have on patients’ day-to-day activities and quality of life.

# CHICAGO

## Medical text books

To a patient with ME/CFS, the attitude of their general practitioner towards the illness can have a big impact on how quickly they are diagnosed, how sympathetically they are treated, and their access to healthcare services. Yet we know that a large percentage of GPs (roughly half in one 2005 study) don't believe the condition actually exists — despite official and authoritative confirmation of the reality and seriousness of the illness by various reports, such as the 2002 CMO report and the 2007 NICE guideline. And we know from phone calls to the charity that patients on the ground can struggle to find an understanding doctor willing to take their illness seriously.

Medical education has a role to play in forming attitudes, particularly text books which, though not usually as up-to-date as articles in scientific journals, are often also used as a source of references and reviews. One group at DePaul University in Chicago recently set out to

understand more fully how ME/CFS is represented in medical text books. They selected a total of 119 mostly US published books in a variety of areas (including immunology, pathology, internal medicine and psychiatry), and reviewed the number of pages mentioning “CFS” and whether that information included any mention of aetiology, classification, diagnosis, recommended treatments or prevalence. Importantly, they also noted whether the text specifically mentioned the term myalgic encephalomyelitis, “ME”.

Their results (published in the *Australian Journal of Primary Health*) are unsurprising and disheartening. Only 40.3% of the books they reviewed included any information on “CFS”, and only 16% had any mention of “ME” terminology — far smaller proportions than for other less prevalent illnesses, such as multiple sclerosis (57%) and Lyme disease (55%). In fact, the topic took up a paltry 116.3 pages (0.09%) of the 129,527 total reviewed.

Of course, less is known about ME/CFS than these other conditions, but even so, these books might have been expected to cover an illness estimated to affect between 400,000 and 900,000 people in the USA, which is where most of the textbooks were published. Such chronic under-representation of ME/CFS in medical textbooks surely serves to reinforce, and possibly legitimise, the prevailing scepticism about this condition.

# LONDON

## A FINE surprise?

From 2003 to 2009, the vast bulk of the £3.1 million spent by the Medical Research Council on ME/CFS research went into two clinical trials.

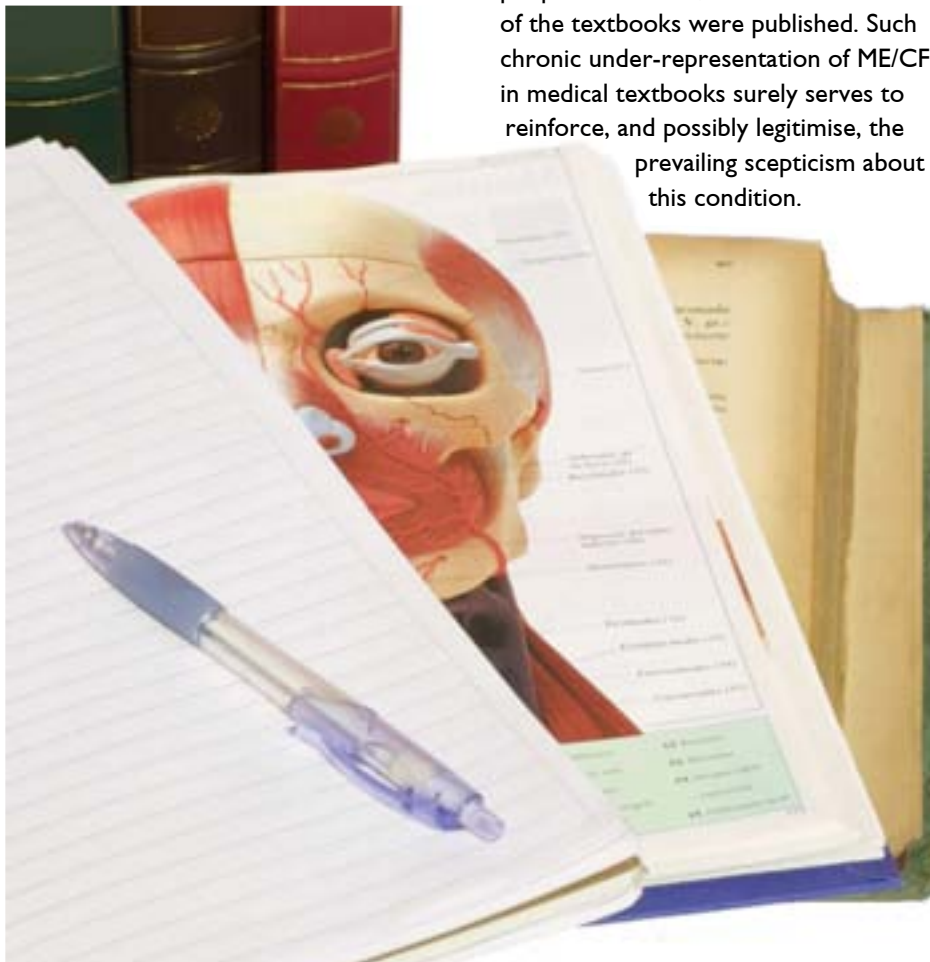
The largest was the PACE trial which compared cognitive-behavioural therapy (CBT), graded exercise (GET) and pacing, and which has yet to report its results. The other study was the FINE (Fatigue Intervention by Nurses Evaluation) trial in which severely affected patients were randomly allocated to one of three treatment groups: “pragmatic rehabilitation”, a nurse-led self-help approach which included elements of CBT and GET delivered in the patients' homes; supportive listening; or usual care provided by their GP.

The first results of the FINE trial, the cost of which exceeded £820,000, were reported recently in the *British Medical Journal*. A total of 296 adults with ME/CFS were enrolled, and after 20 weeks of treatment, patients receiving pragmatic rehabilitation were significantly less fatigued and depressed, and were sleeping better than those who received usual care (although there was no difference in physical functioning).

However, when the participants were seen one year later there was no longer any difference between these two treatment groups. Thus, while pragmatic rehabilitation appeared to help fatigue and depression in the short term, over a longer period it was no better than usual care provided by a GP (with supportive listening having no extra benefits at all).

Are these negative results a surprise? Not really, given that pragmatic rehabilitation does not, and was never intended to, address the pathophysiological basis of disease in these severely ill people.

The real surprise (which is discussed more fully in the July 2008 issue of *Breakthrough*) is that most of the MRC's inadequate grant-spend on ME/CFS has gone to fund trials of non-specific management and coping strategies, at the expense of truly biomedical research — the reverse of the situation in other illnesses such as multiple sclerosis or rheumatoid arthritis.



# The Friends in "A Hard Day's Fundraising"

## Tribute Act Concert

Amy and Sue Bakewell were interviewed by BBC Radio Leicester at the time of the tragic case of Lynn Gilderdale, since Amy is very seriously affected with ME and has lived in isolation in her dark bedroom for 14 years. After this, the presenter visited Amy and offered to organise a charity concert to raise funds for ME research, an offer the family couldn't refuse.

The performances at the concert were all tribute acts: The Fib Four as the Beatles, Micky Vegas as Elvis Presley, and Cliff-As-If as Cliff Richard. They all gave a super evening's entertainment at Thornton Working Mens Club, and the extremely well-supported event raised £850.

Sue explains, "Two days before the concert on 12th May, ME Awareness Day, BBC Radio Leicester broadcast its mid-morning show from our village shop. It was great fun, incorporating interviews with customers, our local ME support group, and Amy. We were pleased to be helping to raise the profile of ME with this excellent publicity."



## Pyjamathon

To mark ME Awareness Week 2010, Annalisa McGorlick wore nothing but pyjamas for 7 days (as proved above)!

She explains, "At the risk of being locked up, I went around in pyjamas, indoors and outdoors, rain or shine, to the pub, to the supermarket and everywhere else. I had to do something, since our government puts £0 into biomedical research for this illness, but without financial backing research cannot be carried out and this life-destroying illness will continue to go untreated and unrecognised."

Annalisa's ME symptoms became severe at age 16, and now after a long, hard journey and various treatments, she is able to live a semi-normal life and to go out a few times a week — hence the "Pyjamathon". She was very pleasantly surprised with the public reaction which was one of support and intrigue, and raised £240 from the event.



## Bucket collections

The aficionados of the Worcestershire ME Support Group, Pauline and Mike Pearson and Warwick Davis (pictured) got together with the Solihull and South Birmingham ME Support Group to hold bucket collections for ME Research UK.

In the summer they headed for Beckett's Farm Shop at Wythall and Evesham Country Park shopping and garden centre with their ME information stand and buckets, raising over £930.

The group is very active, and its monthly informal gatherings are held under the auspices of County Co-ordinator Jill Pigott. Many thanks to all its members for supporting this event.

## London Marathon 2010

Virgin London Marathon day was a great festival of fun for everyone involved. ME Research UK has benefited greatly from London Marathon runners in the past. In 2008, Robert Ogden, Madhi Choudhury and Ian Bottomley ran for us, as did Harvey Gurry and Matthew Fielding in 2009. And this year, we were honoured to have two champions who again used their individual places to run on our behalf.

One of the runners was Dan Plant whose sister had ME some years ago but has since made a wonderful full recovery, so he wanted to help raise funds for research. He says, "After a lot of training, I made it on the day and gave it my best shot — something of a miracle in itself for someone who previously considered lifting a few pints as exercise."

Our other runner was James Albiges (pictured below), who over the last few months has seen the debilitating effect of ME first hand so wanted to raise money for a cause close to his heart. His aim was "to beat 4 hours and then retire gracefully". Both did very well: Dan crossed the line in 4.41.20, and James in 3.56.37, beating his 4-hour target!



## Mayor of Hastings

Hastings' new Mayor, Kim Forward, took up her post at the annual mayor-making ceremony in May. Proposing her, a fellow Councillor said, "Kim relates to all the people she meets with warmth and genuine interest in their well-being. These qualities will be invaluable in her new civic role." In her speech of acceptance Mayor Forward promised to bring energy and enthusiasm, and to promote the interests of Hastings and St Leonards, beautiful places which have so much to offer.

Mayor Forward has chosen to support three charities in her mayoral year: the NSPCC, Care for the Carers and ME Research UK. Her 14-year-old son has had ME for some time, and is now able to walk again although his recovery from the debilitating illness has been slow.

We wish Kim a successful year in office, and send her our grateful thanks for choosing us as one of her supported charities.



## Run, Simon, Run!

Simon Patchitt's Bristol 10k run during ME Awareness Week was a great success. "It's the first time I've been in any kind of race since sports day in 1994," says Simon, who crossed the finish line in 56 minutes and 38 seconds. "I really enjoyed it, even though I needed oxygen in the medical tent afterwards!" (As it turned out, the nurse remembered him from school!)

Linda, Simon's girlfriend, has had ME for almost 10 years. She says, "Many sufferers (like me) are severely affected, but because they often can't go out, no one sees them, so nobody realises how ill they are." She saw the run as a great chance to raise awareness about the impact of ME.

Linda and Simon collected £1,085 from the event — more than double their target. "We're so pleased; thanks to everyone who sponsored the run." Since the race, Simon has kept up the running and has entered the Bristol half marathon in September.

## Greg loses his hair

Greg Carslaw from Birmingham promised himself that he'd wait a decade before getting a haircut. But after 8 years he thought a trim might be nice, and his friends suggested that they might even donate money to charity to see it cut.

But the deal was complex. If he managed to raise £100, Greg would cut off half his hair (head, beard, eyebrows, nasal-hair, whatever). But after that, for every £41.26 raised (amount selected by arbitration) he'd shave off half his remaining hair. This meant that if everyone he knew offered up a fiver, he'd be left with one eyebrow. As an added bonus, whichever generous person gave the most money would have the option to specify some intermediate cut style which Greg would have to wear for 24 hours.

The photo shows Siz, eager with the shears to do a lot of lopping — a threat she carried out a few days later. Greg raised over £500, so thanks to him and all his mates.



# MERUK in the Media

*We've made quite a fizz in the past 6 months.*

## Children's study media coverage

The publication of the University of Dundee's scientific study of children with ME/CFS (see page 8 of this issue) got extensive publicity. On 7th September, things kicked off with Prof. Jill Belch on the BBC Radio 4 Today programme, and continued throughout the day with regular items on BBC News, BBC World Service and BBC Radio regional broadcasts, with ITV taking up the cudgels later in the day. At the same time, a plethora of items appeared across the Internet — on BBC Health, Top News Network USA, WebMD Health News, Scottish Television, UKwired News and Pharmaceutical Live.

Thereafter, the printed media covered the story widely on 8th September. The Times kicked off with a half-page "Study proves that the illness is not psychological", and there were items in the Herald De Paris, Daily Mail Online, Nursing times, the Scotsman, the Los Angeles Times, and an editorial in the Lancet.

## Broadcasts on Real Radio

Real Radio is part of one of the country's largest radio stations, and operates across the UK. For a week from the 16th to 20th August, we had a series of 40-second adverts highlighting five different cases of ME (one each day) and the need for research into the illness. For example, Wednesday's case described "31 year old Liz was teaching biology in a high school when she got a viral infection and become so ill she was off work for five months... That was 24 years ago..." These broadcasts have been very well received, raising awareness of the reality of living day-to-day with ME.

## Herald Scotland Opinion Piece

A 600-word opinion piece by Dr Neil Abbot, "Why we need to start treating ME much more seriously", was published in the Herald newspaper on 27th July 2010, and can be read on-line.



**If you think your story would make a good subject for similar programmes and would be happy speaking about your case to the media, please let us know — we'd love to hear from you**



## Shop at Amazon for ME Research UK

Can there be any easier way to earn money for our charity? If you are buying from Amazon, then just click through the link on the Amazon page on our website, and 5% or more of your purchases could be making its way back to ME Research UK. It really is that simple.

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