

# The Scottish Parliament & M.E.

## Sessions of the Parliament:

- The parliament is currently in its 3<sup>rd</sup> session, beginning 13<sup>th</sup> June 2007
- Session 2 ran from 4<sup>th</sup> June 2003 – 2<sup>nd</sup> April 2007.
- Session 1 of the parliament ran from inception in 1999 to 31<sup>st</sup> March, 2003.

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## Petition of the CPG on M.E.

**2<sup>nd</sup> October 2001** (Session 1): Cross Party Group on ME Petition Lodged

The aims of the petition were to:

- carry out a Strategic Needs Review Assessment on ME and CFS in Scotland
- establish the size of the ME and CFS population
- establish the proportion severely affected and establish their Benefits entitlement & uptake
- establish a centre of excellence for the treatment of and research into ME and CFS
- ensure that GPs are informed about the advances in diagnosis and treatment
- ensure the GPs are informed about the new centre and liaise with it.

The petition featured intermittently at Petitions Committee and Health Committee until **26<sup>th</sup> April 2005** (session 2), when it was closed at Health Committee.

There was considerable debate and discussion of related issues on this occasion and some extracts are presented below.

### April 2005, closure of CPG Petition at Health Committee

Full text of proceedings: <http://www.scottish.parliament.uk/business/committees/health/or-05/he05-1202.htm>

#### Extracts:

*Rhona Brankin:* We have set up a short-life working group on chronic fatigue syndrome and myalgic encephalomyelitis. We asked NHS boards to advise us of progress on the planning of services for people with CFS and ME; in particular, we asked whether they had carried out needs assessments. If so, a copy of the conclusions was requested. We also asked whether it had been possible to identify any sources of expertise in their areas, what contact had been made with the voluntary sector, and what proposals the boards had for the future planning of CFS and ME services.

I believe that the boards have given that information to the committee. We have made the responses available. As part of the service change framework, we are setting up a working group to consider how best to manage all chronic conditions.\* We have just given grant funding to the voluntary organisation Action for ME to develop information for general practitioners. We will arrange for an assessment of need as soon as possible. We will also fund NHS Quality Improvement Scotland to produce a best practice statement on ME as part of its current work programme.

The information that we have received from the short-life working group and, subsequently, from NHS boards shows that provision is patchy—there is no doubt about that. In a sense, that links into the questions about, and the broader issue of, how health boards are supported and encouraged and how they are accountable for providing the best quality of service for patients with a range of conditions.

We must now move to assessment of need in order to take the issue forward; we will make arrangements for an assessment of need to take place as soon as possible. As I have said, we will also fund NHS QIS to produce a best practice statement on ME as part of its current work programme.

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\* Outcome was the 'Kerr Report': *Building a Health Service Fit for the Future*, Scottish Executive, May 2005. Andy Kerr, then Health Minister, spoke in the Parliamentary Chamber regarding the publication of this report, May 25<sup>th</sup> 2005.

Health boards were asked for information on ME/CFS because it is necessary to have some clarity on the scale and scope of the problem to inform our work in future. We need to obtain that baseline information, although we must acknowledge that different health boards started from different positions.

Janis Hughes: I have a final question; I am conscious that other people want to come in on the debate. The petition suggests that there is a pressing need for a specialist Scottish ME clinic. What are your views on that?

Rhona Brankin: When we receive the report on the management of chronic conditions,<sup>\*</sup> we will have to consider such possibilities, but at the moment there are no specific plans for such a clinic in Scotland. Because there has been no assessment of need, it is difficult for me to give a firm indication of our plans. The fundamental issue is that we get an assessment of need, consider what comes out of the NICE guidelines, look at the NHS QIS best practice statement and look for the best configuration of services for people with ME/CFS.

Janis Hughes: That demonstrates how important it is that we have the assessment. How long do you envisage it taking?

Rhona Brankin: At the moment, I can say only that we will make arrangements for an assessment of needs as quickly as possible. I am happy to keep in touch with the committee on that, because I know that it has a significant interest in the matter, as does the cross-party group, which I am meeting in June. I undertake to keep in touch with the committee and the cross-party group on the timescales.

Shona Robison: Will you consider ways of ensuring that the needs assessment does not take as long as two years, as has been suggested? If it takes two years, that will be a five-year delay from when the short-life working group was first mooted in 2002—such a delay would be unacceptable to all the patient groups and individuals who are hoping and waiting for an assessment of needs. I urge you to speed up the process as much as possible.

Rhona Brankin: It is not the case that nothing has happened: progress in local health boards is somewhat patchy, but we have made progress. I would certainly want the needs assessment to be undertaken as quickly as possible.

As a former teacher and lecturer, I am conscious of the issues relating to pupils with special educational needs. Indeed, I have worked with children with ME and chronic fatigue syndrome and am aware of the current debate around psychiatric and neurological approaches. I have an open mind on the issue and would be concerned if you were to interpret what has been said today as being an endorsement of a purely psychiatric approach. I would want us to be open minded about the issue. Having worked with young people in schools, I am aware that the condition can be explained in many different ways. We must not close our minds. We need to be confident that we have the very best information, which is why we have to examine closely the NICE guidelines and ensure that we have access to the research that is being done around the world.

I am certainly keen to work closely with the various representative bodies on chronic fatigue syndrome and ME. Ministers and other politicians have a huge amount to learn from people who have had those conditions and from the experience of the families of those people. I am happy to do that.

Alex Fergusson: I am delighted to hear that the Scottish Executive is not taking a purely psychiatric approach, minister. When you visit the cross-party group on ME, you can expand on that point. Do you acknowledge that ME is a different disease from CFS? Do you recognise it as being a neurological disease? Do you recognise it as being a chronic condition, which will be considered by the relevant care sub-group? You might have already answered the last question, but I would like you to clarify your position.

Rhona Brankin: As I said, I am aware that there are various schools of thought on the issue. I think that there are strong grounds for viewing ME as a neurological condition, but I would not want to say to you that my mind is closed to other views. I know that there is considerable debate and discussion about the issue, but my professional experience of contact with people who suffer from ME suggests to me that it is a neurological condition. Clearly, however, I am not an expert and must be guided by what people say to me. I will therefore take guidance from medical advisers, but I also need to listen to what I am told by people who have had experience of the conditions and by their families.

I cannot predict what the review [*i.e.* the HNCA] will come up with, but I have said that ensuring that there is an accurate assessment of needs is important. As the Deputy Minister for Health and Community Care, I will look closely at what the review throws up. We must ensure that there are the

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<sup>\*</sup> Again, this refers to the 'Kerr Report': *Building a Health Service Fit for the Future*, Scottish Executive, May 2005.

highest-possible standards of treatment and the best advice for people who suffer from ME and chronic fatigue syndrome.

One reason for the Kerr review considering the management of chronic disease is to ensure that there is the best-quality treatment throughout Scotland for chronic conditions. Obviously, ministers will carefully consider Professor Kerr's hugely important report and, following the needs assessment, I intend to consider how we can ensure that the best-quality assessment, treatment and support are provided throughout Scotland.

Perhaps we could also consider the development of services at the general practitioner level, for example where GPs are looking to develop a specialist interest, as they are increasingly looking to do. There is no doubt that the curriculum is crowded and it is sometimes difficult for all GPs to have access to the most up-to-date information on every condition that is known to man. That is undoubtedly a challenge for them. I hope that the development of specialist GPs will help in that regard.

*NOTE: A petition concerning epilepsy was also considered at this meeting, and Rhona Brankin made reference to developments regarding neurology in Scotland in this connection – but not when speaking to the ME petition. Neurological care standards were launched March 2010.*

## Parliamentary Debates

**January 2002 - Motion for Debate S1M (session 1 motion) - 2402#**

**Alex Fergusson (South of Scotland) (Conservative): Research into Myalgic Encephalomyelitis —**

That the Parliament notes the privately funded research to be carried out by Dr Derek Pheby in Bristol, and that being carried out by Dr Vance Spence in Dundee, into the factors which may be involved in the development of severe myalgic encephalomyelitis (ME); recognises that ME is a condition growing in incidence among both adults and children in Scotland, and considers that the Scottish Executive should take the lead within the UK by commissioning further research under the remit of the NHS into the causes of, and cures for, this debilitating condition.

Full text of proceedings can be accessed at:

<http://www.scottish.parliament.uk/business/officialReports/meetingsParliament/or-02/sor0123-02.htm#Col5660>

**Extracts:**

**The Deputy Minister for Health and Community Care (Hugh Henry):** The debate is timely, given the publication this month of the report of the English chief medical officer's working group on care for people with ME or—for those who prefer to use the other definition—CFS/ME.

We are all aware that, as many members have said, conclusive knowledge of the cause and development of this condition has eluded the best efforts of researchers. That elusiveness can too easily lead to frustration when we see the impact that ME can have on our nearest and dearest, particularly children. Alex Fergusson spoke movingly of the direct impact that the condition has had on Christopher and the way in which he has had to face up to a significant change in his life.

I congratulate members on the positive and informed debate that we have had on a difficult subject. John McAllion is right to draw attention to the number of members who requested to speak and who have attended the debate and to the number of people in the public gallery. That is significant and reflects the fact that this debate deals with a growing problem. One of the difficulties with the willingness to participate is that I cannot possibly cover all the issues that were raised tonight. That is an indication that there has to be a longer and more informed debate in Scotland about ME.

**Bruce Crawford (Mid Scotland and Fife) (SNP):** Does the minister agree that there must be not only more research, but a change of culture at the heart of Government and in all organisations that are associated with Government? The culture must be changed to reflect the fact that ME exists and to ensure that action is taken and that barriers are removed rather than obstacles being created. If we consider the problem from that perspective, we can make substantial changes.

**Hugh Henry:** Bruce Crawford is right: there is a need to change the culture. Winnie Ewing and others referred to the need to change the culture in the medical profession, Robin Harper spoke about education and John McAllion and others spoke about the problems in the wider NHS. I agree that the culture in Government must change significantly as well.

The report of the English chief medical officer's working group on care for people with ME is welcome for a number of reasons. It should lay to rest the controversy over whether the condition is real, which has

sometimes been a barrier preventing sufferers from obtaining good-quality care. It is important that the report gives due weight to the views and experiences of patients.

**Linda Fabiani (Central Scotland) (SNP):** Is the minister aware of tests that have been carried out in the United States of America and Europe? DNA testing has identified the presence of bacteria in the cells of ME sufferers—those bacteria are difficult to find. That seems to detract from the idea that ME is psychological and psychosomatic. Is the minister willing to examine that research with a view to having similar research carried out in Scotland to try—once and for all—to negate the myth that ME is a psychologically caused disease and to find out whether there is a physical cause?

**Hugh Henry:** I will return to research later.

The debate gives us an opportunity to state clearly that some of the myths, scepticism and prejudice that have existed should be consigned to the past. Alex Fergusson, Christine Grahame and others have spoken about sufferers whom they know. I, too, have a close relative who has suffered. One point that has been echoed tonight is that a sufferer can go from being active—and almost, in my relative's case, from having to be chained down to stop them going to work when they were not well—to being suddenly physically incapable of going out of the house, not understanding what is wrong with them and not being able to turn to anybody who can give them assistance and advice. We must consider that.

Another welcome feature of the report is its emphasis on the need for evidence-based practice. Because so much remains unknown or uncertain about the condition, it is easy to assume that there has been little research. That is not true: there have been more than 1,000 medical research publications. As we speak, nearly 30 research studies are being carried out in the health service. As is often the case, the quality of the published research varies widely and care is needed in its interpretation.

Susan Deacon and others made some useful suggestions. She spoke about the need for action now that the report is published and about a mechanism to take the report forward. John McAllion spoke about identifying how we support the needs of ME sufferers. We will respond to those requests by setting up a short-life action group to consider over three months the most effective ways of improving the care and quality of life for those with ME.

The information from that group will be made available to the NHS at all levels in Scotland. Speakers tonight have been right: we need to ensure that doctors and everyone else who is involved in the NHS are aware of the findings of the report and, more important, of some of the things that could and should be done to support ME sufferers.

The report's findings form a good platform on which to base our future research effort. We need to identify interventions that can be incorporated into routine clinical practice and to find out which therapies work best for which groups of patients. A number of speakers have mentioned the need for more research. Janis Hughes, Margaret Smith, Lord James Douglas-Hamilton, Nicola Sturgeon and Bristow Muldoon all correctly emphasised that need. However, research cannot be a substitute for action; we need to consider that.

The working group acknowledged in the report the lack of good evidence on incidence, prevalence and trends and recommended further research. The Department of Health in England has asked the Medical Research Council to draw up a research strategy, taking account of the working group's findings, other recent expert reviews and the views of patients and carers. The work will be advanced by an independent scientific advisory group. It is appropriate to state that the MRC is a United Kingdom body. It funds research projects throughout the UK and has frequent contact with our chief scientist office. We support the initiative to establish such a strategy and will provide whatever help we can. Until that strategy is available, it would not be sensible for the Executive to commission large-scale studies. There are also disputes about definitions.

Once the MRC's work is complete and the future strategic direction of research is clear, we shall of course be seeking to play our full part in the implementation of the strategy. We are not convinced at present of the arguments for a centre of excellence, but we need to consider some of the further research. Good-quality research proposals into other aspects of the syndrome will be considered by the chief scientist office through the usual peer review process.

Those who suffer from ME are a well-organised group of people, who have right and justice on their side. The fact that so many people are now suffering makes it imperative for us to respond appropriately. We must take people who suffer from ME out of the shadows of being regarded as cranks, malingerers and people who are trying to avoid facing up to reality. ME is a specific medical problem and, as members have said, we need to change attitudes and culture. We must ensure that local authorities, health services and others have the information that they need to provide a proper service to people who suffer from ME.

**The Deputy Presiding Officer:** That concludes the debate. I give our best wishes to those members of the public in the gallery.

**Alex Fergusson: A Cure for ME? —**

That the Parliament notes with pleasure that a scientific team from Glasgow University, headed by Dr John Gow, may have discovered a remedy for myalgic encephalomyelitis (ME) which could be available in as little as year; further notes that the university has already patented the genes involved as a means of diagnosing the condition quickly and cheaply; recognises that this could represent a major step forward in the treatment and cure of this debilitating disease but notes with alarm Dr Gow's concern that he is "going nowhere" because his funding has run out, and considers that the Scottish Executive should take every possible step to ensure that this work can be continued in order that the 10,000 to 20,000 ME sufferers in Scotland can play a full part in the economic and social life of their country.

Full text of proceedings can be accessed at:

<http://www.scottish.parliament.uk/business/officialReports/meetingsParliament/or-05/sor0609-02.htm#Col17885>

**Extracts:**

**The Deputy Minister for Health and Community Care (Rhona Brankin):** I, too, congratulate Alex Fergusson on his success in obtaining the debate. I am sure that his tireless efforts, as convener of the cross-party group on ME, to improve services for people with chronic fatigue syndrome and ME are greatly appreciated by those who are affected by this complex and distressing illness. The number of members who have attended tonight's debate, at the end of a long day, shows the high degree of interest that the issue attracts in the Parliament.

Contrary to what Alex Fergusson says, the Executive takes CFS/ME seriously. We have taken and continue to take steps to improve services. I will say more about that later. We are supporting research that we hope will lead to improved treatments in the future.

However, the motion refers to a particular research project. The lead researcher, Dr Gow, is aware of the role played by the chief scientist office in the Scottish Executive Health Department in encouraging and supporting research into health and health care needs in Scotland. As Alex Fergusson knows, the CSO responds primarily to requests for funding for research proposals that are initiated by the research community in Scotland and would welcome proposals for innovative CFS/ME studies of a sufficiently high standard. I cannot discuss any specific applications in detail—the CSO rightly keeps applications confidential until decisions on funding have been reached—but I can say that the chief scientist office would be prepared to discuss Dr Gow's research further with him. All applications for CSO funding are assessed on their quality and relevance to the health of the people of Scotland, using a well-established and highly regarded system of peer and committee review. It is important to note that there are lay members on all the CSO's committees. I will ask to be kept up to date on that issue.

The chief scientist office works in partnership with the Medical Research Council to support research on CFS/ME. The report of the independent working group on CFS/ME to the chief medical officer in England in January 2002 identified a need for a wide-ranging programme of research, and the MRC was asked to develop a strategy for advancing biomedical and health services research in this area. That approach was endorsed by the Scottish short-life working group on CFS/ME, which was set up by the chief medical officer in Scotland following publication of the English report.

In taking forward the strategy, the MRC encourages research proposals in all aspects of CFS/ME, including studies into the causes of the condition as well as evaluations of treatments. Proposals that are received under the initiative will benefit from additional weighting when they are assessed in competition for MRC funds, as CFS/ME has been designated as a current priority area for research. Although scientific quality has to be the main criterion, CFS/ME is a priority area for research.

As has been discussed today, funding for two large clinical trials has already been approved as part of the CFS/ME strategy and the CSO is contributing £250,000 over five years towards the cost of one of them. However, the MRC remains committed to funding scientific research into all aspects of CFS/ME and is currently considering a number of other applications on which funding decisions will be taken shortly.

I say to David Davidson that it is not the case that the Scottish Executive does not support genetics in health care. In fact, we have recently funded a major initiative on genetics and health care throughout Scotland to the tune of £4.4 million. That is a hugely exciting development. Some very exciting work on genetics has gone on in recent years at the Roslin Institute in my Midlothian constituency. It is clear that research into genetics is hugely important for Scotland.

Robin Harper spoke about advice on CFS/ME. The widening of the definition of additional support needs in the Education (Additional Support for Learning) (Scotland) Act 2004, which comes into force later this year, could have potential benefits for affected youngsters. Some youngsters with CFS/ME come to the notice of teachers because they sometimes have an erratic attendance at school. I am happy to ask Peter Peacock,

the Minister for Education and Young People, whether some specific reference to CFS/ME can be made in relevant guidance. Although I am not sure whether it is possible to make reference to all conditions, it would be useful to provide information for teachers. Having been a teacher who has worked with youngsters with CFS/ME, I am aware of the kind of difficulties experienced by such youngsters and their families.

**Alex Fergusson:** Is the minister aware of an initiative that was launched jointly last year by the Tymes Trust for ME sufferers and a Japanese company, the name of which escapes me? They put together an information technology distance learning package specifically designed for people with conditions such as CFS/ME. If she is not aware of that, will she undertake to look into it to see whether it might have application in the delivery of education to sufferers in Scotland?

**Rhona Brankin:** I am not aware of that initiative. I have been out of the teaching profession for a number of years, but if the member gives me some information on the initiative, I will be happy to consider it and discuss it with Peter Peacock.

On the wider issues of services for people with CFS/ME, we set up a short-life working group on chronic fatigue syndrome and myalgic encephalomyelitis and we asked NHS boards to advise us of progress on the planning of services for people with CFS/ME. As has been discussed, the responses from health boards showed that, although they all took the report seriously, services remained patchy. In a way, that is understandable, because the boards were not all starting from the same place. Some of them had already begun work on improving services, but others were only beginning to scope out the problem. It was clear that much more work was needed, and we have now agreed to arrange a national assessment of needs.

We recently received the report of the working group on the management of chronic conditions, which was set up as part of the national framework for service change.\* Of course, that report relates to all long-term illnesses, but it has an important message on chronic conditions for all of us. We will consider its recommendations for improvements.

We have recently given grant funding to the voluntary organisation Action for ME to develop information packs for general practitioners. That work has already been done in England, and it is hugely important.

I am happy to reaffirm the commitments that I made to the Health Committee on 26 April. We will arrange for an assessment of needs as soon as possible and we will fund NHS Quality Improvement Scotland to produce a best-practice statement on ME as part of its current work programme.

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Helen Brownlie

July 2010

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\* The 'Kerr Report'. *Building a Health Service Fit for the Future*, Scottish Executive, May 2005. Andy Kerr, then Health Minister, spoke in the Parliamentary Chamber regarding the publication of this report, May 25<sup>th</sup> 2005.