

Members of the Scottish Parliament :
Interest & Involvement in Matters related to M.E.

prepared by Helen Brownlie
on behalf of the 25% ME Group
July 2010

MSPs and M.E.

This guide is intended to help you get the most out of lobbying your Members of the Scottish Parliament on issues relating to M.E. It contains an alphabetical list of current MSPs who have had some involvement or shown an interest at some point, or who currently hold Government or Shadow positions relevant to M.E. matters. The guide includes details of MSPs' participation in some Scottish Parliamentary 'landmark' events regarding M.E and related issues, and other indications of interest such as the submission of Parliamentary Questions on M.E. matters.

Contacting MSPs

If you have internet access then you can find out who your Members of the Scottish Parliament are by going to the website - www.scottish.parliament.uk - and clicking on the link to 'MSPs' on the home page (middle box towards the top). There are instructions to identify your constituency MSP and regional list MSPs, who can be e-mailed directly from their listing here – just click on 'contact details'. The postal address for MSPs is: *The Scottish Parliament, Edinburgh EH99 1SP*.

MSPs who are ministers in the Scottish Government, can be contacted in their Ministerial capacity at scottish.ministers@scotland.gsi.gov

Parliamentary ‘Landmarks’

The major Scottish Parliamentary events have been:

<i>Autumn 1999 onwards</i>	Cross Party Group on M.E.
<i>October 2001</i>	Petition on M.E. matters lodged with Petitions Committee. The petition featured intermittently at Petitions Committee and Health Committee until 26 th April 2005, when it was closed at Health Committee. The aims of Petition are listed below.
<i>23rd January 2002</i>	Debate on motion seeking research funding
<i>2nd March 2005</i>	Cross Party Group holds a reception at the Parliament
<i>26th April 2005</i>	Petition Closed at Health Committee with announcement of plans for an assessment of need and statement of best practice.
<i>6th June 2005</i>	Debate on Motion regarding Dr Gow’s research funding

Cross Party Group Petition

The aims of the petition were:

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

Parliamentary Debates

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

Alex Fergusson (South of Scotland) (Con) : Research into Myalgic Encephalomyelitis — That the Parliament ... 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.

June 2005 – *Motion for Debate S2M (session 2 motion) - 2852 #* (extract)

Alex Fergusson: A Cure for ME? — That the Parliament 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. *[More on this debate, including the announcement of funding for a GP guide, at entry for Rhona Brankin MSP.]*

For detail on the petition, motions and debates a companion paper – ‘The Scottish Parliament and M.E.’ is available. (HelenB-25megroup@ntlworld.com or phone 01292-318611)
And the Cross Party Group’s recent paper ‘10 year campaign for health care founded on biomedical research’ gives an overview of events in Parliament and the efforts of the CPG.

Parliamentary Questions

Parliamentary Questions on M.E. and related matters and Ministerial Responses are placed below under the entry for the MSP who asked the question(s).

See entries for Stewart Stevenson (PQs 2004), Lewis MacDonald (2005 – responding to question from former MSP Janis Hughes), Bruce Crawford (PQs 2005, 2006 and 2007), Andy Kerr (PQs 2007), Jim Tolson (PQ 2008), Jamie Stone (PQ 2009), Willie Coffey (PQ 2009), John Wilson (2009) and Mary Scanlon (PQs 2009 and 2010).

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Bryan ADAM (SNP) Aberdeen North

Bryan Adam is on the contact list for Cross Party Group, but hasn't attended for a while / so far.

He was a substitute member on the Health Committee from May 2002 to March 2003 so may be aware of the CPG Petition.

He supported the motion for debate regarding Dr Gow's research and uncertainty over funding for same, June 2005.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

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Bill AITKEN (Conservative) Glasgow list

Bill Atiken supported the motion for debate in June 2005

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Jackie BAILLIE (Labour)

Dumbarton

Jackie Baillie was on the Public Petitions Committee in the second session of the Parliament. However, this Committee had little to do with the Cross Party Group on M.E.'s petition at this time, as it had been referred to Health Committee.

While she may have little awareness of matters relating to ME, she has been involved in health issues more generally. Following a brief period on the Health Committee, she currently holds the position of Shadow Cabinet Secretary for Health and Wellbeing.

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Sarah BOYACK

(Labour)

Edinburgh Central

Sarah Boyack attended the CPG's Parliamentary Reception held to mark ME Awareness Week in May 2010.

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Rhona BRANKIN (Labour)

Midlothian

Rhona Brankin is a former Deputy Health Minister. In this capacity:

- She has provided written response to Parliamentary Questions on M.E. (March 2005: details below);
- She provided the executive's position at Health Committee when the Cross Party Group on ME's petition was closed. (April 2005: details below.)
- She responded to the debate on a motion presented by Alex Fergusson regarding Dr Gow's research. (June 2005: details below.)

3rd March 2005, response to Parliamentary Questions

S2W-14600 - Mr David Davidson: To ask the Scottish Executive whether it will match on a per capita basis the investment in developing CFS/ME services in England.

Rhona Brankin: The Executive prefers to maximise the unified budgets made available to NHS boards for the treatment of all chronic conditions, rather than hold back funds for specific conditions.

S2W-14599 - Mr David Davidson: To ask the Scottish Executive whether it intends to develop a managed clinical network for CFS/ME sufferers.

Rhona Brankin: The development of managed clinical networks must be led from within the NHS. NHS boards who wish to participate in a network must prepare a case and may then apply to the Executive for support.

S2W-14598 - Mr David Davidson: To ask the Scottish Executive whether it has any plans to replicate the new services being rolled out in England for sufferers of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).

Rhona Brankin: The Executive takes the view that the planning of services is best carried out by NHS boards based on their assessment of local needs. NHS boards have been encouraged to consider what they can do to improve services for people with CFS/ME.

April 2005, closure of petition at health committee - Extracts from committee proceedings

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

Rhona Brankin: 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.

...

Janis Hughes: 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,* 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.

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: I would certainly want the needs assessment to be undertaken as quickly as possible.

Rhona Brankin: ...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: 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? ... 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

* The outcome was the 'Kerr report': *Building a Health Service Fit for the Future*, Scottish Executive, May 2005.

* See note above.

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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.

... We must ensure that there are the 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.

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.

June 2005, response to motion and debate - Extracts from proceedings:

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

The Deputy Minister for Health and Community Care (Rhona Brankin): 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.

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.

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.

* 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 25th 2005.

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Ted BROCKLEBANK (Conservative) Mid Scotland & Fife list

Supported the motion for debate, June 2005

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Robert BROWN (Liberal Democrat)

Glasgow list

Robert Brown was a substitute member of Health Committee in an earlier session of Parliament (September 2003-July 2005) – so he may be aware of the Cross Party Group's Petition and its closure.

He supported the motion for debate in January 2002.

More recently, he responded to a request to approach the NHS Board in his area regarding under-use of tilt tables to test for problems relating to low blood pressure (this request originated from a suggestion made at Cross Party Group, drawing on Julia Newton's presentation to CPG regarding problems related to low blood pressure in people with ME.)

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Bill BUTLER (Labour)

Glasgow Anniesland

Bill Butler was a member of Health Committee in the first session of the parliament, at which time the Cross Party Group on ME's petition was petition was under consideration.

He supported the motion for debate in June 2005.

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Malcolm CHISHOLM (Labour) Edinburgh North & Leith

Malcolm Chisholm was briefly member of Health Committee in the current session (June-September 2007).

He hosted the Scottish neurological standards launch in March 2010.

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Willie COFFEY

(SNP)

Kilmarnock & Loudoun

Willie Coffey has submitted a Parliamentary Question on M.E.:

S3W-24413: To ask the Scottish Executive, further to the answer to question S2W-7080 by Tom McCabe on 1 April 2004, what additional services for people with chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) have been established since February 2003.*

Written Answer, Thursday, 4 June 2009, Nicola Sturgeon (Scottish National Party)

Service developments since February 2003 include the employment of a CFS/ME nurse specialist in NHS Fife and the development of a CFS/ME assessment clinic in NHS Lothian. A programme for people with CFS/ME has also been developed by the Centre for Integrative Care at the Homeopathic Hospital, Glasgow. We are funding an evaluation of that programme to help promote its dissemination.

In order to encourage further progress in the development of services, we commissioned the Scottish Public Health Network (SPHN) to undertake a needs assessment for CFS/ME, and last month it issued a draft for consultation. It contains recommendations on a proposed model of care for Scotland, including the development of a Managed Clinical Network approach to ME-CFS (to use the Network's preferred terminology).

In tandem with the needs assessment, we have also provided Action for ME with funding to produce a first edition of a Good Practice Statement on ME-CFS. This is intended to help general practitioners with the management of ME-CFS until such time as the evidence base allows the development of a clinical guideline by the Scottish Intercollegiate Guidelines Network.

* **Mr Tom McCabe:** A framework for the provision of services for CFS/ME sufferers in Scotland was developed by a short life working group, set up by the Executive, and commended to NHS boards in February 2003. The Executive has asked boards for reports on action taken in the light of the working group's report and has undertaken to convey the outcome to the Health and Community Care Committee.

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Cathy CRAIGIE

(Labour)

Cumbernauld & Kilsyth

Cathie Craigie attended the Cross Party Group's Parliamentary Reception to mark ME Awareness Week in May 2010.

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Bruce CRAWFORD

(SNP)

Stirling

Bruce Crawford is a former convenor of Cross Party Group on ME. In his present position of Minister for Parliamentary Business in the Office of the First Minister in the present Scottish Government he has been unable to continue involvement in CPG. However, he did attend the CPG parliamentary reception for ME Awareness week in May 2010.

Back in January 2002 he put this question to the then Deputy Minister for Health & Community Care following the debate in Parliament:

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.

Ministerial response (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.

Bruce Crawford has also asked a number of Parliamentary Questions:

S2W-19356 Bruce Crawford: To ask the Scottish Executive what the remit is of the strategic needs assessment it is undertaking in respect of ME;

S2W-19357 Bruce Crawford: To ask the Scottish Executive who has responsibility for undertaking the strategic needs assessment in respect of ME and what level of support is available to carry out the assessment effectively;

S2W19358 Bruce Crawford: To ask the Scottish Executive when it expects the strategic needs assessment in respect of ME to be completed and how it will publish the results.

Lewis Macdonald: (3rd October, 2005) - *response to all of the above* - The Executive is committed to carrying out an assessment of needs for ME services. It has, however, proved difficult to identify the best means of taking this forward. The former Scottish Needs Assessment Programme has been in abeyance for some years and the infrastructure which supported it no longer exists. After consideration of all options the Executive has decided that the work must be put out to tender. This will be done as soon as the financial resources to support it can be identified.

S2W19359 Bruce Crawford: To ask the Scottish Executive what level of financial resources it makes available to NHS boards to help treat those who are affected by ME.

Lewis Macdonald: (3rd October, 2005) NHS boards are given unified budgets, increased by an average of 7.6% in the current financial year, from which they are expected to meet the costs of treatment for people with ME and all other chronic conditions. It is for boards to decide how their unified budgets should be distributed, based on their assessments of local needs.

Bruce Crawford: To ask the Scottish Executive what level of support is provided by each NHS board for ME sufferers.

Lewis Macdonald: (3rd October, 2005) The information requested is not held centrally.

S2W-23507 Bruce Crawford: To ask the Scottish Executive, further to the answer to question S2W-19357 by Lewis Macdonald on 3 October 2005, when it expects to put the contract for providing an assessment of needs for ME services out to tender; when the tender process will be complete, and how much it will cost.

Lewis MacDonald (10th March 2006): The Executive is committed to carrying out an assessment of the service needs of those with CFS/ME and the financial resources for the assessment have been identified. We are still considering the best options for obtaining an independent assessment, and ensuring that the arrangements conform to procurement requirements. We also want to make sure that the specification for

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the tender will deliver the intended outcomes. I hope to be able to make an announcement in the near future which will include the information requested in the Question.

S2W-23508 Bruce Crawford: To ask the Scottish Executive, further to the answer to question S2W-19357 by Lewis Macdonald on 3 October 2005, whether it will list the companies or organisations that will be invited to tender to provide an assessment of needs for ME services.

Lewis MacDonald (10th March 2006): The Executive will follow the procedures laid down for tendering exercises, and will be happy to make public the names of those organisations which submit a bid to undertake the assessment.

S2W-23508 Bruce Crawford: To ask the Scottish Executive, further to the answer to question S2W-19357 by Lewis Macdonald on 3 October 2005, what patient involvement there will be in the tendering process for providing an assessment of needs for ME services.

Lewis MacDonald (10th March 2006): In taking forward the tendering process, we shall consider how people with ME/CFS, and those representing their interests, can most effectively contribute.

S2W-32390 Bruce Crawford: To ask the Scottish Executive who the members are of the public health network referred to by the Minister for Health and Community Care in a letter to me of 8 January 2007 and on what basis each member was selected.

Andy Kerr (28th March 2007): The Scottish Public Health Networks (ScotPHNs) remit is to facilitate joint working between all organisations involved in health improvement and health services by providing a means of communication, through specific projects in areas of national importance, and to do this the Network consists of a Steering Group which is chaired by a Director of Public Health. Its membership is drawn from key individuals from relevant organisations such as Directors of Public Health and Medical Directors from Special Health Boards. It agrees and guides the ScotPHN work programme.

Governance of the Network is undertaken by a Stakeholder Group. These stakeholders include broad representation from organisations responsible for delivering health improvement and health service, such as Directors of Public Health; Consultants in Public Health Medicine; Health Promotion Managers; Public Health Specialists; Public Health Academics; Public health colleagues from Special Health Boards; Community Health Partnership General Managers or Clinical Directors; Dental Public Health; Pharmaceutical Public Health and Environmental Health Specialists.

S2W-32391 Bruce Crawford (Mid Scotland and Fife) (SNP): To ask the Scottish Executive what the remit is of the public health network referred to by the Minister for Health and Community Care in a letter to me of 8 January 2007; what the networks objectives are, and how its work is monitored.

Mr Andy Kerr (27th March 2007): *reference to remit, as above ..* The objectives of the Network are to:

- undertake prioritised national pieces of work where there is a clearly identified need, which will impact on planning and decision making at both national and local level. This will be facilitated by using the skills, knowledge and expertise, which are spread widely across Scotland, in addressing public health issues; and
- to create effective communication amongst professionals and the public to allow efficient co-ordination of public health activity. To share information effectively so that duplication of effort is avoided.

The Network has a Steering Group which is chaired by a Director of Public Health. Its membership is drawn from key individuals from relevant organisations. It agrees and guides the ScotPHN work programme. *Reference to 'Stakeholder Group', as above ...* The ScotPHN is facilitated and monitored by a lead clinician with the support of a project manager. The ScotPHN is hosted by NHS Health Scotland.

ScotPHN is open to everyone in Scotland who has a professional interest and significant involvement in the wider health improvement agenda including staff from the NHS, local authorities, academia and others. The ScotPHN work programme is still under development as it has been fully functioning for less than 6 months.

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Roseanna CUNNINGHAM (SNP) Perth

Roseanna Cuninghame was chair of Health Committee in session 2 of the Parliament; in this capacity chaired the meeting of the Health Committee at which the petition was closed. (See extracts below.)

She supported the motion for debate, June 2005.

(Roseanna Cuninghame is currently Minister for the Environment in the Scottish Government.)

Contributions from Roseanna Cunningham, from the record of Health Committee (April 2005):

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

Opening the discussion: The petitions have been under consideration by the committee for a considerable time, and have been the subject of extended correspondence with a variety of ministers over the years. Today's session will focus on the outstanding questions and issues that have been raised with the committee in recent submissions from the petitioners. As agreed at the committee's meeting on 1 February, consideration of the petitions will be closed on the basis of today's session.

Closing the discussion: Some progress has been made today. Everybody, including the petitioners, will welcome the strategic needs assessment. However, the history of this process has been very unedifying. The petitioners first asked for a needs assessment, and that was followed by the announcement of a short-life working group, which was presumably to progress matters faster and "provide suggestions for improvements ... more rapidly" .

Sometime later, however, there was a turnaround and it was decided that, because there was no needs assessment, nothing further would happen.

In a sense, we are right back where we were at the start of the petition. The set of events in the intervening years has been unfortunate. Although I appreciate that the minister is at the sticky end of the lollipop and that the matter had nothing to do with her in the first place, I ask her to suggest to her department that that is no way to proceed. It now looks as if the short-life working group was nothing more than a delaying mechanism, which is unfortunate and not a very sensible way to proceed. That is not what the group was meant to be but, as a result, we have lost time.

Response from Rhona Brankin, Deputy Health Minister:

Let me say something in defence of the department. I do not take the view that there has been no progress. However, when one considers the reports coming back from the boards, one can see that, although the boards were starting from different places, progress has been very patchy. Given that, an assessment of needs will allow us to take things forward.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Helen EADIE (Labour)

Dunfermline East

Helen Eadie was deputy convenor of the Public Petitions Committee when the CPG on ME's petition was lodged, remaining in that position until March 2003. She continued to be a member of the Petitions Committee throughout the 'life' of the CPG petition, and was also a member of the Health Committee at this time, so she may well recall the Petition and its aims.

Helen Eadie is a member of the Health Committee in the current session of parliament.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Fergus EWING (SNP)

Inverness East, Nairn & Lochaber

Fergus Ewing spoke to the motion for debate in January 2002. (Details below.)

He also supported the motion for debate in June 2005.

He is currently Minister for Community Safety in the Scottish Government.

January 2002:

Fergus Ewing: I congratulate Alex Fergusson warmly on securing the debate. I imagine that it must have been a difficult speech for him to make. I am sure that we are all aware that ME has touched his family and that we wish Christopher well.

About a year ago, I received a letter from a constituent. I spoke to her today. She does not want her name or her daughter's name to be mentioned, but she said that I could call her daughter Georgina. Her letter read:

"I am writing to you to highlight the problems faced by people with ME, and to appeal to you to do all you can to further research and understanding in this area.

This is a poorly understood condition, which some Doctors still fail to acknowledge as real, and not 'all in the mind'. This illness can have a devastating effect on the sufferer and their family made worse by the prejudice and lack of understanding surrounding it.

It is time the Government did something about ME. It is real and does not go away if you ignore it. Many young people are affected with consequent waste of potential, and cost to the country in supporting someone with a long-term illness. These people, in addition, often face an extremely long wait, while waiting to hear about Disability Benefits, all the while being ill and in need of the financial help.

My eleven-year-old daughter 'Georgina' has suffered from ME for 4 years now. As a family we have found this extremely difficult. At the moment she is very disabled, being bed-bound most of the time, needing a wheelchair to get around, and a full time carer to help her at all times. She has had episodes of fever, suffers from chronic pain in her limbs, headaches, nausea, severe abdominal pain, sleep disturbance, severe exhaustion all the time, and now in addition "fit-like" episodes of severe muscle twitching. This is her third severe relapse. She was hospitalised in 1998 for 9 months with associated anorexia, and accompanying problems all associated with ME."

In all the speeches that I have made in the chamber, I have never read out so much of a letter. I did so because I could not improve on the description that my constituent gave of the tragic plight of her and her daughter, who suffers the dreadful condition. As any other MSP would, I took up her case with the relevant authorities and received fairly sympathetic responses from Heather Sheerin of Highland Primary Care NHS Trust, who described the process of diagnosing the disease as a diagnosis of exclusion, and from the previous Minister for Health and Community Care. I am sure that all members subscribe to the proposals that Alex Fergusson described.

Since that letter was written, Georgina has spent four months in Yorkhill hospital and was in a coma—or shutdown, as some call it. Recently, she has come out of that and is making progress. I praise the neurological ward at Yorkhill, which has given my constituent and her daughter some succour.

I hope that the debate will lead to a slightly better understanding of this dreadful disease.

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Linda FABIANI (SNP)

Central Scotland

Linda Fabiani signed the motion and participated in debate, January 2002. (Details below.) Linda Fabiani had also wished to speak to the motion, but there wasn't enough time to fit in her contribution.

She supported the 2005 motion for debate also.

She was a member of the Public Petitions Committee in the second session of the Parliament, however the committee had little involvement with the CPG on ME's petition at this time, and she was no longer a member by the time the petition was closed (at Health Committee).

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?

Ministerial response from Hugh Henry: I will return to research later. ...

The [English CMO's Group's] 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.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Alex FERGUSON (No Party Affiliation)

Galloway & Upper Nithsdale

Alex Fergusson was a founding member of the Cross Party Group on ME and has served as Convenor and Deputy Convenor.

He lodged both motions for debate (January 2002 and June 2005) and spoke eloquently to these motions in Parliament.

He attended Health Committee when closure of the Cross Party Group's petition was under consideration, advocating further consideration of the demands of the petition rather than closure at that point.

As Presiding Officer of Parliament in the current session, Alex Fergusson has had to withdraw from Cross Party Group and adopt a lower profile on political matters. However, he did attend the CPG parliamentary reception to mark ME Awareness Week in May 2010.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Ross FINNIE (Liberal Democrat)

West of Scotland list

Ross Finnie is currently deputy convener of the Health Committee

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Rob GIBSON (SNP)

Highland & Islands Regional List

Rob Gibson supported the 2005 motion for debate.

He *may* have some awareness of the CPG on ME's petition, as he has been a substitute member of the Public Petitions Committee. (He joined committee as substitute September 2003, when the CPG petition had already been lodged, and remained substitute member throughout the 'lifetime' of the petition.) However, substitute members can only attend meetings when a full member of the committee from their party cannot make the meeting, and the petition was largely in the lap of the health committee during this period.

He has shown interest more recently - although Rob Gibson isn't a member of the Cross Party Group on ME, a representative of his attended the Group's November 2009 meeting. The meeting heard two presentations on research: (1) by Dr Susanne Hagan, who was working with Dr Gow on potential genetic biomarkers, and (2) by Dr Marilyn McNeil, a medically qualified member of the CPG, who gave a summary overview of the US study that identified XMRV.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Charlie GORDON (Labour)

Glasgow Cathcart

Charlie Gordon is a member of the Cross Party Group on ME and regularly attends CPG meetings. He also attended the CPG reception for ME Awareness Week in May 2010.

His constituency leaflet for the last Scottish Parliamentary election stated: *Charlie supports better services for sufferers from M.E. (myalgic encephalomyelitis)*

In November 2005 he attended a meeting at which Dr David Reilly gave a presentation concerning the 'Wellness Enhancement Learning Programme for Patients with CFS/ME' funded by the Greater Glasgow NHS Board, which had then just begun to operate. (Dr Reilly is lead clinician on this service.)

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Christine GRAHAME (SNP)

South of Scotland List

Christine Grahame was on the Health Committee between June 2003 and September 2004, holding the position of deputy convenor of the committee for much of that time. So she would have been aware of the CPG on M.E.'s petition, though she was no longer on the committee when the decision was taken to close the petition.

She is convener of the Health and Sport committee in the current session of Parliament.

She signed the 2002 and 2005 motions and participated in both debates in the Parliament, and has also asked a Parliamentary Question (see Jan 2002 debate – below - for details):

January 2002 debate: I say "Well done" to Alex Fergusson and John McAllion for their work on the cross-party group on ME. I cannot get to the group's meetings often enough because of other commitments.

I came to the group because I have a friend with ME. If one sees him in the good times, it is hard to believe that he was once in a wheelchair. I know that he must be going through a bad time now because his e-mails have stopped. He is very politically active. I get hordes of e-mails and then there is silence for months. I have discovered that, at the moment, he hardly has the energy to switch on a television or follow anything. The swings and roundabouts of this dreadful illness are what brought me to the cross-party group.

I asked him what I should talk about in this debate, and he mentioned the issue that was raised at the cross-party group meetings, which was benefits. People with ME find that benefits are a problem; for example, the disability living allowance form asks questions such as the number of steps that applicants can climb. The point is that although those people might have been able to do it yesterday, they cannot do it today and they do not know whether they will be able to do it tomorrow. My friend has had the illness for decades and explained that he copes with it by managing it. However, if something goes wrong—for example, if he does something in a hurry—it might then take him two or three hours even to put his hand to his face in order to shave. Although the World Health Organisation has recognised this peculiar but real illness, I must stress that ME sufferers' huge difficulties with benefits have been severely neglected. People have to go through many appeals before any benefits might be granted.

Robin Harper mentioned young children, who face great difficulties with having their illness recognised. I must point out that there are problems with professionals in this respect.

Before I finish, I want to mention the written parliamentary questions on this subject that I asked when Susan Deacon was minister. In one question, I asked whether the Scottish Executive would "undertake a national audit of the services which are available to those who have myalgic encephalomyelitis." —[*Official Report, Written Answers*, 22 May 2001; p 249.] I was advised that I should wait for the report. Now that the report (*English CMO's Working Group*) has been published, will the minister undertake an audit of the available services? Furthermore, will he answer the other questions that I lodged about involving professionals in understanding the illness to get rid of any prejudices and the idea that it is simply psychosomatic?

June 2005 debate: It is a pleasure to support Alex Fergusson on his long pilgrimage to have some serious effort put into providing a cure for ME. He knows that I became involved after a friend of mine was diagnosed with ME. My friend has ended up in a wheelchair. He can now manage things to some extent, but, as ME is a spasmodic illness, he has bad spells. I have said in the chamber before that sometimes, when he does things too fast, the electrics go awry and he has to spend hours trying to shave. It takes ages before he can work his way back again.

It has taken an inordinately long time to discharge the label of yuppie flu. Thankfully, that is no longer around, although the thought still lingers in some people's minds that people with ME are "at it". Perhaps a minority of people are, but someone cannot be "at it" when they are in a wheelchair or when, if they do something quickly, they are debilitated for a long time afterwards.

I want to mention the impact on and the difficulties for people with ME in accessing benefits; an issue that I have raised previously in the Parliament. If we do not pursue a cure, sufferers will be disadvantaged in several ways, because the tests that are applied for disability benefits are not relevant to someone with ME. They might be asked if they can walk up stairs or do certain tasks; of course, on one day they are able to do them and pass the test, but they might not be able to function for many days and weeks thereafter. They face a double whammy: they have an illness for which there is a possibility of a cure that is not being pursued and they are also denied the assistance that is given to others who have illnesses that are, in some respects, visible. I welcome the debate. I am sure that Alex Fergusson will be successful one day, as his determination certainly bowls me over. I hope that it bowls the minister over.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Rhoda GRANT (Labour)

Highlands & Islands List

Rhoda Grant was a member of Petitions Committee at the time the Cross Party Group petition was lodged (session 1 of the parliament).

She is member of the current Health Committee.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Iain GRAY (Labour)

East Lothian

Iain Gray is leader of the Scottish Labour Party. He attended to hear the presentations at the CPG reception for ME Awareness Week in May 2010.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Robin HARPER (Green)

Lothians List

Robin Harper supported the 2002 and 2005 motions for debate and participated in both debates (see below).

He is a member of the Cross Party Group (but rarely if ever attends).

January 2002: On behalf of Tommy Sheridan and myself, I congratulate Alex Fergusson on bringing the debate to the chamber. It has been extremely informative. Before the debate, I took the subject of ME seriously. I take it even more seriously now.

I will restrict my remarks to expressing one concern, which is about what happens to young people at school who are diagnosed with ME, or to those who suffer from ME but have not been officially diagnosed. In such cases, although the child has not been officially diagnosed, the parents might suspect that their child suffers from ME. Although I have no evidence to substantiate this, I suspect that there might be an inconsistency in local authorities' guidance on education provision for young people who suffer from ME. That might be because there is a tendency to live in hope—there is no hurry to take action when a child has ME because they might be back next month, in six months' time or after a year—but if a child suffers from ME, there is a great deal of urgency for the appropriate education to be given. From my experience, home education is a possibility; schools can arrange for work to be sent home. We need something more structured than that as soon as young people are suspected of suffering from ME, let alone diagnosed.

Ministerial Response (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.

June 2005: I am happy to support the second motion on ME in Alex Fergusson's name that we have debated. I remember that, during the first debate, I reflected on my experiences as a teacher of young people who suffered from ME. At that time, I called on the Executive to issue specific advice to teachers on helping young people who have ME, but it appears that nothing has happened in the interim. A survey of 445 members of the Association of Young People with ME showed that 80 per cent drop out or fall behind in their education because of their illness.

I was e-mailed only yesterday by a constituent whose son is now 20 and has lost seven years of his education because of ME—seven years of his life and 50 per cent of his possible education in school have been removed from him forever. It is vital that we protect the health of children who have ME. Experienced paediatricians confirm that teachers who do not understand ME are a key cause of relapses in young children.

I will make one point in the debate. My researchers checked with the Scottish Parliament information centre, which said that the Executive has not published specific guidance to teachers to support pupils who have ME, despite the call that was made in the previous debate. Will the minister ask the Education Department whether it will issue to all guidance teachers in Scotland specific instructions and advice for helping all pupils who suffer from ME?

It is possible that there is a specific reference to ME in the code of practice on additional support needs. I would welcome the minister's advice on that. Will the code of practice provide specific information on ME? I contend that it must. I thank Alex Fergusson for bringing the issue to Parliament's attention again and I support fully his call to the Executive to provide real funding for research, which could—at last—provide the answer for everybody.

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Patrick HARVIE (Green) Glasgow list

Patrick Harvie responded to a 2009 request to approach the NHS Board in his area regarding under-use of tilt tables to test for problems relating to low blood pressure (this request originated from a suggestion made at Cross Party Group, drawing on Julia Newton's presentation to CPG regarding problems related to low blood pressure in people with ME.)

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Hugh HENRY (Labour) Paisley South

Hugh Henry was Deputy Minister for Health and Community Care in Session 1 of the Parliament. In this capacity, he gave the ministerial response to the motion debated following publication of the English CMO's Working Group report in January 2002.

(The motion is set out on page 3 above – and elements of Hugh Henry's response can be found under the above entries for Bruce Crawford, Linda Fabiani, and Robin Harper. For his response in full see companion paper '*The Scottish Parliament and M.E.*' – details on page 3 above.)

Hugh Henry attended the CPG's Parliamentary reception to mark ME Awareness Week in May 2010.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Cathy JAMIESON (Labour) Carrick, Cumnock & Doon Valley

Cathy Jamieson was Minister for Children and Young People in Session 1. In this capacity she was guest speaker at Cross Party Group on ME in February 2003.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Andy KERR (Labour)

East Kilbride

Andy Kerr was Health Minister in Session 2 of the Parliament, and in this capacity provided written responses to several Parliamentary Questions on ME (see entry for Bruce Crawford, above).

He has been convener of the Cross Party Group on ME since autumn 2007.

Andy Kerr has asked several Parliamentary Questions:

S3W-07384 Andy Kerr (East Kilbride) (Lab): To ask the Scottish Executive whether it will list all managed clinical networks, showing the disease groups covered by each.

S3W-07385 Andy Kerr (East Kilbride) (Lab): To ask the Scottish Executive whether it will provide contact details for all managed clinical networks.

Shona Robison (12th December 2007): - *response to both of the above* - The information available centrally is given in table *Managed Clinical Networks*, a copy of which is available in the Parliament's Reference Centre (Bib number 44254).

S3W-07386 Andy Kerr (East Kilbride) (Lab): To ask the Scottish Executive what funding has been given to bio-medical research into chronic fatigue syndrome and myalgic encephalomyelitis (ME) since 1999.

Shona Robison (12 December 2007): The Chief Scientist Office (CSO), of the Scottish Government's Health Directorates, which has responsibility for encouraging and supporting research into health and health care needs in Scotland, is collaborating with the Medical Research Council (MRC) on the implementation of its research strategy into chronic fatigue syndrome and myalgic encephalomyelitis (CFS/ME). Since 1999, neither the CSO nor the MRC have funded any bio-medical research into this condition. Both the CSO and MRC would be pleased to consider proposals for such research into CFS/ME which would be subject to the usual peer and committee review.

The National Research Register (NRR), a UK wide research database, records that there are currently 22 projects ongoing in the UK on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), of which 4 are bio-medical research projects. Details of these projects are available from the NRR, which is available at www.nrr.nhs.uk.

S3W-07387 Andy Kerr (East Kilbride) (Lab): To ask the Scottish Executive what responses it is making to Inquiry into the status of CFS/ME and research into causes and treatment, the Gibson Report, published in November 2006.

Shona Robison (12 December 2007): The Gibson report was produced by the Group on Scientific Research into ME, which consists of a number of members of the UK Parliament at Westminster. It deals with an issue which is devolved to the Scottish Parliament, but has not, so far as I am aware, been presented formally to the Parliament. There has therefore been no formal response from the Scottish Government.

We asked Action for ME, however, to take account of the contents of the Gibson Report in undertaking the preliminary scoping exercise for which we provided them with funding.

S3W-07389 Andy Kerr (East Kilbride) (Lab): To ask the Scottish Executive what health-related centres of excellence it supports or has supported since 1999.

Ms Nicola Sturgeon (12th December 2007): The term "centre of excellence" could be applied to many types of organisation and facility in health related areas.

In terms of the research, the following centres are currently supported through the Chief Scientist's Office:

- The Health Services Research Unit, Aberdeen
- The Health Economics Research Unit, Aberdeen
- The Dental Health Services Research unit, Dundee
- The Institute for Hearing Research, Glasgow
- The Research Unit in Health, Behaviour and Change, Edinburgh
- Social and Public Health Sciences Unit, Glasgow
- Nursing, Midwifery and Allied Health Professions Research Unit, Stirling and Glasgow
- Scottish Institute for Life Sciences, Dundee

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John LAMONT (Conservative) Roxburgh & Berwickshire

John Lamont is a member of the Cross Party Group on ME, but isn't a regular attender.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Marilyn LIVINGSTONE (Labour) Kirkcaldy

Marilyn Livingstone signed the 2002 motion for debate.

She is a member of the Cross Party Group on ME, but isn't a regular attender.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Kenny MacASKILL (SNP)

Edinburgh East and Musselburgh

Kenny MacAskill currently holds the Ministerial post of Justice Secretary. He attended the Cross Party Group's parliamentary reception for ME Awareness Week in May 2010.

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Lewis MacDONALD (Labour) Aberdeen Central

Lewis MacDonald was Deputy Health Minister in session 2 of parliament. In this capacity he attended Cross Party Group meeting November 2005, and responded to a number of parliamentary questions posed by then convener of the CPG, Bruce Crawford (see entry above), as well as this question from Janis Hughes (who is no longer an MSP) in December 2005:

(S2W-20924) Janis Hughes : To ask the Scottish Executive what funding it has awarded for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) services or research since the CFS/ME short-life working group reported in 2002.

Lewis Macdonald: NHS Boards are given unified budgets, increased by an average of 7.6% in the current financial year, from which they are expected to meet the costs of services for people with CFS/ME and all other chronic conditions. It is for NHS Boards to decide how their unified budgets should be distributed, based on their assessments of local needs.

The Chief Scientist Office (CSO), within the Scottish Executive Health Department, has responsibility for encouraging and supporting research into health and health care needs in Scotland. CSO is currently contributing £250,000 to the Medical Research Council project Pacing, Activity and Cognitive behaviour therapy: a randomised Evaluation (PACE), which compares different approaches to the clinical management of patients with CFS/ME.

Lewis MacDonald is a past member of the Health Committee in the current session of Parliament.

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Paul MARTIN (Labour) Glasgow Springburn

Paul Martin has been a substitute member of Health Committee (from September 2003-June 2005), so may have some awareness of ME issues as the Cross Party Group petition was considered and closed during this period.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Tricia MARWICK (SNP) Central Fife

Tricia Marwick signed the 2002 and 2005 motions for debate.

She may have attended reception held by Cross Party Group on ME, March 2005.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Stewart MAXWELL (SNP)

West of Scotland list

Stewart Maxwell was a substitute member of the Health Committee from September 2004 and remained so when the Petition was closed the following April.

MSPs can be e-mailed directly from the list at -
www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Frank McAVEETY (Labour) Glasgow Shettleston

Frank McAveety was Deputy Health Minister in Session 1 of the parliament, and in this capacity attended Cross Party Group on ME in June 2002.

He is currently a substitute member of the Health Committee

MSPs can be e-mailed directly from the list at -
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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Tom McCABE (Labour) Hamilton South

Tom McCabe was for a time Deputy Health Minister in the second session of the Parliament. In this capacity, he attended the September 2003 meeting of the cross Party Group on ME. He also responded to several parliamentary questions on ME matters (see entry for Stewart Stevenson for details).

MSPs can be e-mailed directly from the list at -
www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Michael McMAHON (Labour) Hamilton North & Bellshill

Michael McMahon was convener of the Petitions Committee in session 2; however, the Cross Party Group's petition was considered only briefly during this period, with the agreement that it be referred to the Health Committee.

Michael McMahon attended the Cross Party Group's Parliamentary reception, held during ME Awareness Week in May 2010.

MSPs can be e-mailed directly from the list at -
www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Duncan McNEIL (Labour) Greenock & Inverclyde

Duncan McNeil was on the Health Committee in Session 2 of the Scottish Parliament, while the Cross Party Group petition was being considered, and at the point when it was closed.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Nanette MILNE (Conservative)

North East Scotland regional list

Nanette Milne was on the Health Committee in session 2 of the Parliament, at which point the Cross Party Group on ME petition was being considered, and closed.

She signed the 2005 motion for debate.

She responded as follows to lobbying against closure of the petition:

"I'm sure that you, along with most other people involved with the Cross Party Group on ME, were disappointed by the Health Committee's decision to conclude the Group's petition at its meeting of 26th April.

As a member of the Committee, I thought long and hard about any further action which could be taken but in view of the Deputy Minister's statement that an assessment of needs would be undertaken as soon as possible, and that NHS Quality Improvement Scotland would be issuing a statement of best practice and producing best practice guidelines for Scotland, I could really see no alternative but to close the petition at that point in time.

I do accept, however, that pressure needs to be kept up on the Executive, so that ME is not relegated again to the 'back burner', particularly at a time when research in the field of genetics appears to be yielding some promising results.

I am pleased, therefore, that my colleague Alex Fergusson MSP has submitted a Members' Motion on the subject, which I have signed in the hope that it will soon be debated in the Parliament.

I will continue to liaise with Alex in trying to keep ME to the forefront of the Executive's thinking, and I will continue to support the Cross Party Group – even though I have been unable to attend its recent meetings."

(response to CPG member by e-mail, June 2005)

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

John Farquhar MUNRO (Liberal Democrat)

Ross, Skye & Inverness West

John Farquhar Munro was a member of the Petitions Committee in the first two sessions of the Parliament, during the 'lifetime' of the Cross Party Group on ME's petition.

He supported the 2002 motion for debate on ME research.

In 2005, he participated in the debate on a motion regarding ME research (see below).

He also attended the Cross Party Group on ME's reception in 2005.

John Farquhar Munro is a longstanding member of the Cross Party Group on ME and, until the current session of parliament, he was a faithful attender at CPG meetings.

John Farquhar Munro (Ross, Skye and Inverness West) (LD): I am delighted to take part in the debate and I congratulate the convener of the cross-party group on ME, Mr Fergusson, on securing the debate. He does a tremendous amount of work on the cross-party group and has done much to promote the issues surrounding the condition.

Until recently, the medical profession has not supported pleas from ME sufferers and has considered the condition to be more or less a yuppie flu. Whenever anybody presented themselves with ME, the doctors gave them the sloped shoulder, handed them a box of tablets and said that they would be all right the next week. The truth is that ME can strike at any time and can be most frustrating. Young adults who are fit, healthy and active are suddenly struck down and become lethargic, listless and morose. Great problems are created in families in which that happens.

Steady progress has been made on the issues through the cross-party group. That group has been assisted tremendously by the regular attendance, professional support and experience of the group members, many of whom have suffered from ME over many years or have witnessed members of their immediate family becoming listless, lethargic and morose. We are indebted to them for that professional support.

We have heard about the recent medical research, which appears to have developed a simple and effective cure for ME. That is excellent news, which must be publicised and promoted by health officials. It will be very much welcomed by the large number of people who have suffered with the condition over many years.

Now that we have established a potential cure for the ailment, which was, until recently, hardly recognised or accepted by many people in the medical profession, let us not miss the opportunity to lead the world in the research, development, treatment and cure of ME, which has been a scourge on our society for many years. I hope that the Executive can be encouraged to support financially the excellent work that has already proved to be so successful in the treatment of ME.

The information available to us suggests that only modest amounts of money are required to make the historic, groundbreaking research nationally and internationally recognised. The costs would be minimal, but the benefits to ME sufferers could be gigantic.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Elaine MURRAY **(Labour)** **Dumfries**

Elaine Murray attended the Cross Party Group's Parliamentary Reception to mark ME Awareness Week in May 2010.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Shona ROBISON (SNP) Dundee East

Shona Robison signed the 2002 and 2005 motions for debate, regarding the need for government research funding in respect of M.E.

She was a member of the Health Committee in the first and second sessions of the Parliament, during which time the Cross Party Group on M.E.'s petition was considered and closed. She participated in the discussion at committee (26th April 2005) by asking then Deputy Health Minister Rhona Brankin:

Will you consider ways of ensuring that the needs assessment [newly announced at committee] 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 to process up as much as possible.

(The Minister responded: *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.*)

Around this time Shona Robison came along to a meeting of Cross Party group on ME with other SNP MSPs to indicate an interest. Unfortunately, the timing of CPG meetings then clashed with SNP meetings, so they were not able to attend on a regular basis.

Shona Robison is now Minister for Public Health and Sport, and in this capacity she has responded to Parliamentary Questions on ME matters (see entries for Andy Kerr MSP and Mary Scanlon MSP).

In common with other Ministers in the Scottish Government, she can be contacted in her Ministerial capacity at scottish.ministers@scotland.gsi.gov

MSPs can be e-mailed directly from the list at -
www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Mike RUMBLES (Liberal Democrat) South of Scotland regional list

Mike Rumbles was a member of the Health Committee in the second session of the parliament, when the Cross Party Group's petition was being considered and closed.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Mary SCANLON (Conservative) Highlands & Islands regional list

Mary Scanlon was a member of the Health Committee in the first session of the Parliament, and a substitute member during the second session, so she may well have been aware of the Cross Party Group petition and its aims. (She is a member of the present Health Committee also.)

Mary Scanlon was a signatory to the 2002 and 2005 motions for debate, regarding the need for government research funding in respect of M.E.

Mary Scanlon has been a member of the Cross Party Group on ME during the current Parliamentary session and took the role of vice convener for a time.

She has asked several Parliamentary Questions relating to 'myalgic encephalopathy':

S3W-18980 Mary Scanlon: To ask the Scottish Executive what is being done in public sector organisations to assist people with myalgic encephalopathy to remain in employment.

Shona Robison (14 January 2009): Where an individual with Myalgic Encephalopathy is sufficiently impaired as to meet the definitions of the Disability Discrimination Act 2005, a public sector employer would be required to meet their duties under the Act.

The Disability Discrimination Act 2005 introduced a public sector duty to promote equality for disabled people. This duty came into force in December 2006 and requires all public authorities to be proactive in tackling discrimination against disabled people and to look at ways of promoting equality for disabled people. Public authorities covered by the specific duties (which includes local authorities) must produce a disability equality scheme setting out the action they will take. All functions of the public body are covered by the duty, including their role as an employer.

The Scottish Centre for Healthy Working Lives can provide advice to employers on measures that they can take to ensure compliance with the Disability Discrimination Act, through its website, telephone helpline and healthy working lives advisors.

S3W-21488 Mary Scanlon: To ask the Scottish Executive what specialist support exists to enable people with myalgic encephalopathy/chronic fatigue syndrome to receive a diagnosis and treatment.

Shona Robison (12 March 2009): NHS Quality Improvement Scotland (NHS QIS) is developing clinical standards for neurological conditions. Standard statement 2 is that patients with suspected neurological disorders are assessed by clinicians who specialise in neurological conditions and patients are assessed within timescales dictated by their clinical needs. NHS QIS published the draft standards for consultation on 24 November 2008, with publication due in summer 2009.

We have provided Action for ME with funding to develop a Scottish Good Practice Statement for GPs on CFS/ME. This is intended to ensure better and more consistent standards of care for patients, including quicker and more reliable diagnosis of the illness and agreed clinical/diagnostic criteria for CFS/ME. The advice is due to be published in the near future. It is expected to include information about the specialists to whom GPs might make a referral.

S3W-21489 Mary Scanlon: To ask the Scottish Executive how patients with myalgic encephalopathy / 'chronic fatigue syndrome' can be assured of a consistent level of service in each NHS board area.

Shona Robison (12 Mar 2009): NHS Quality Improvement Scotland (NHS QIS) is developing clinical standards for neurological conditions. Standard statement 1 is that an effective and comprehensive neurological health service is available and offered across all NHS boards. NHS QIS published the draft standards for consultation on 24 November 2008, with publication due in summer 2009.

Other initiatives which will contribute to consistency of services are the Scottish Good Practice Statement on CFS/ME being developed for GPs by Action for ME, and the needs assessment being carried out by the Scottish Public Health Network. A Managed Clinical Network approach would also help to promote consistency of services. /

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

S3W-34147 Mary Scanlon: To ask the Scottish Executive how patient experiences are taken into account in terms of developing Scottish Intercollegiate Guidelines Network (SIGN) Guidelines.

Nicola Sturgeon (14th June 2010): The Scottish Intercollegiate Guidelines Network (SIGN) is part of NHS Quality Improvement Scotland, A Special Health Board, whose role is to support NHS Boards and their staff to improve the quality of healthcare in Scotland.

SIGN has a range of policies to ensure that patient and carer experiences and preferences are included in the development of their guidelines. These include patients focused literature searches, speaking to patient organisations, checking with other NHS organisations whether there is any local research on patient views and seeking direct feedback from service users if required. Patients and other groups also have the opportunity to comment on the draft recommendations and influence their final form through a national open meeting which is held for each draft SIGN guideline. Further detail on these policies is available on the SIGN website as www.sign.ac.uk

S3W-34144 Mary Scanlon: To ask the Scottish Executive how it ensures that patients with chronic fatigue syndrome/ME (or myalgic encephalopathy) are given an accurate diagnosis and treatments tailored to their individual needs.

Shona Robison (15 Jun 2010): Most people with myalgic encephalomyelitis/chronic fatigue syndrome (ME-CFS) will initially present to their general practitioner (GP) for diagnosis and help with management of their condition. GPs, as generalists, are trained to manage all initial contact with patients and deal with all problems. GPs are expected to update their knowledge through continuing professional development (CPD), particularly to suit the needs of their patients, including the annual appraisal process. This seeks to enable GPs to practise high quality medicine, including early recognition and optimal treatment of illnesses such as ME-CFS.

The Scottish Government strongly supports the development of robust clinical guidance to facilitate the proper management of illnesses. Work is under way to produce up to date guidance for use by GPs on the diagnosis and management of ME-CFS, as part of the development of a Scottish Good Practice Statement on ME-CFS.

We want to encourage the development of specialist services to which GPs can refer patients with ME-CFS, as part of a recognised care pathway. The Scottish Public Health Network has therefore been commissioned to undertake a Needs Assessment exercise to determine optimal services for ME-CFS. That work is at an advanced stage.

The Scottish Government is keen to ensure consistently high standards of care for ME-CFS are available throughout NHS Scotland. In January 2010, NHS Quality Improvement Scotland launched Clinical Standards for Neurological Health Services. The generic standards 1-4, in particular, will underpin improvements in services for all neurological conditions, including ME-CFS.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

John SCOTT **(Conservative)** **Ayr**

John Scott supported both motions for debate (2002 and 2005).

He was deputy convener of the Public Petitions Committee in Session 2 of the Parliament, however the Cross Party Group's petition rarely featured at this time (it was under consideration by Health Committee, having been referred there by the Public Petitions Committee).

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Margaret SMITH (Liberal Democrat) Edinburgh West

Margaret Smith was convener of the Health Committee during the first session of the parliament, when the Cross Party Group on ME's petition was under consideration.

She supported the January 2002 motion for debate and spoke to the motion (extracts):

Mrs Margaret Smith (Edinburgh West) (LD): I welcome the ME sufferers who are with us. We can only imagine how difficult it must have been for many of them to take the trouble and the time and to make the effort to join us.

As many as 15,000 Scots have ME. Some are as young as six. A significant number are affected in their teens and early 20s. For many of them, ME means a life without work and without the relationships that could have been formed at that critical stage of their development. It is a life with little hope of recovery: there is no cure for this chronic disabling condition. Twenty-five per cent of sufferers will remain incapacitated—many are bed-bound for the rest of their lives. That is why the research that has been called for is so necessary. ...

One of the most welcome facets of the recent report of the working group in England is its recognition that ME *"is a genuine condition that imposes a substantial burden on patients, carers and families"* because, for many years, elements of the medical profession and the public, reacting to press reports of yuppie flu and the like, dismissed sufferers. That continues today. Sometimes, sufferers continue to be denied the benefits they rightly need because doctors fail to recognise the existence of the condition and its impact. I associate myself wholeheartedly with Alex Fergusson's comments.

The physical impacts vary from patient to patient, which has contributed to difficulties in diagnosis, but the working report sets out that ME *"lacks specific disease markers but is clinically recognisable."*

I am sure that all colleagues have received letters on the subject from constituents. In the past few months, I have met some of them to talk about the issue. The vast majority seem to have had difficulties and delay in being diagnosed. One constituent highlighted the fact that she had to wait six years. When, finally, she was diagnosed, she described it as a "turning point" from which she was able slowly to regain something like a normal life.

Angus MacKay (Edinburgh South) (Lab): ... I want to comment on the point Margaret Smith has made and which has been reflected in other speeches. I do not pretend to be an expert on the subject in any way, shape or form, but what is clear from the briefing we received and from constituents' letters is that the illness, which is painful and difficult to deal with, is but one part of an equation. For many people, a greater part is the thought that, unlike those who may require a heart by-pass or a hip replacement or treatment for a stroke, there is no clear course of action to be taken because GPs and the health service are not placed coherently to diagnose and treat the disease. It is hopelessness that contributes to so many of the problems that are associated with the disease.

Mrs Smith: While asking for a bit more time to continue with my speech, I associate myself wholeheartedly with Angus MacKay's comments: there is the question of diagnosis.

There is also the question of examining a range of different issues. That is why it would be useful to have a centre of excellence that would examine research on the subject. Another constituent pointed out that if services are not in place, *"a diagnosis is as much use as a jelly watch."*

I agree with Janis Hughes: we need to identify exactly what services we need. That is another reason why we need research on the subject.

In the past, clinicians would tell patients that if they continued to feel fatigued they should come back six months later, but the condition would only get worse. We would not accept that attitude from clinicians in other specialist areas such as cancer and we should not expect it in relation to ME.

The latest working group says that *"a 6-week point from onset of abnormal fatigue is a more useful marker"*. That is a move in the right direction.

GPs can undertake screening investigations, but it would be useful for them to be part of a multidisciplinary approach that would see them backed up with physicians, paediatricians, psychologists, therapists and nurses.

Patients need to be listened to. Some of the figures that emerged from the Action for M.E. membership survey are interesting. One said that two thirds of people saw a benefit from a change of diet or when they had been given nutritional supplements. That is an area in which more research should be undertaken.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Shirley-Anne SOMERVILLE (SNP) Lothians regional list

Shirley-Anne Sommerville has joined the Cross Party Group on ME, but hasn't (as yet) attended meetings.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Stewart STEVENSON (SNP) Banff & Buchan

Stewart Stevenson supported the 2002 motion for debate.

In 2004 he posed Parliamentary Questions relating to ME (details below). He made the following comments in a press release with his Parliamentary Questions, lodged to coincide with M.E. Awareness Week:

"Information and support services are needed by people with ME, carers, and health professionals. Even if you do not have ME or use services yourself, you can help others by telling them about existing services. I am certain that M.E. Awareness Week will achieve its aim of making more people aware of M.E. and also enable people to understand what it is like to actually have M.E.

Campaigning in this area will help to improve the situation for people with M.E. Regrettably, there is no treatment for M.E. although there are many different alternative therapies available. Like many others though, I believe that the best thing an M.E. sufferer can do is learn to manage their illness effectively.

Quality of life is so important when it comes to surviving an illness like M.E. so complete nightmare [possibly some words were missed from the press release here]. There are many charity groups that sufferers can join, so they needn't be alone. I am hopeful that M.E. sufferers will feel less isolated, and help others understand how easy it is to become isolated when suffering from such a devastating illness."

Here are the Parliamentary Questions he posed, and the ministerial responses (10th May, 2004):

S2W-7493 - Stewart Stevenson: *To ask the Scottish Executive how many people there are with myalgic encephalomyelitis (ME) in (a) Scotland and (b) each parliamentary constituency.*

Answered by Mr Tom McCabe: *Exact information is not available centrally. Information from samples of GP records in practices across Scotland, whose population is nationally representative, suggests that approximately 6,700 patients with myalgic encephalomyelitis were seen by GPs in the year ended December 2003. However, this complex condition may be recorded in different ways by GPs, which might lead to some significant undercounting. The Executive's Short Life Working Group, on the basis of published prevalence rates and population figures, estimated that at least 10,000 people in Scotland were likely to be affected by ME.*

S2W-7494 - Stewart Stevenson: *To ask the Scottish Executive what initiatives it is supporting in connection with the Myalgic Encephalomyelitis Awareness Week May 2004 campaign.*

Answered by Mr Tom McCabe: *While the Executive is not directly supporting any initiative in connection with ME Awareness Week, it welcomes this annual event and the focus it brings to this distressing condition. The report of a Short Life Working Group on CFS/ME, set up by the Executive, was issued to NHS boards last year. The Executive is currently gathering information on the action NHS boards are taking in response to the report.*

S2W-7495 - Stewart Stevenson: *To ask the Scottish Executive what action it will take in response to concerns about current treatment and resource provision in respect of myalgic encephalomyelitis, as referred to in a recent report published by the 25% M.E. Group, Severely Affected M.E. Analysis Report on Questionnaire Issues January 2004.*

Answered by Mr Tom McCabe: *The 25% M.E. Group is a UK body, and the report referred to is not exclusive to Scotland. It also touches on a number of issues reserved to Westminster. The Executive issued the report of a short life working group, set up to make recommendations for improving services, to NHS boards in February 2003, and is currently seeking progress reports on action taken since.*

S2W-7496 - Stewart Stevenson: *To ask the Scottish Executive what plans it has to extend the resources available to primary healthcare providers for the treatment of myalgic encephalomyelitis.*

Answered by Mr Tom McCabe (10 May 2004): *NHS boards are expected to provide services for people with all chronic conditions from the unified budgets made available to them by the Executive. Unified budgets for 2004-05 were increased by an average of 7.25% more than the 2003-04 allocations, more than twice the rate of inflation.*

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Jamie STONE (Liberal Democrat) Caithness, Sutherland & Easter Ross

Jamie Stone is a substitute member of the health committee in the current session recently asked a number of Parliamentary Questions on ME matters. These received a ministerial response on 23rd Sept 2009:

(S3W-27236) **Jamie Stone:** To ask the Scottish Executive what specialist training is given to frontline health care staff on recognising the symptoms of myalgic encephalomyelitis.

Nicola Sturgeon: GPs are trained to manage all primary contact with patients and to deal with all problems. Their continuing professional development is supported by NHS boards, NHS Education for Scotland (NES), Deaneries and Royal Colleges.

The Scottish Public Health Network's draft needs assessment of services for people living with ME-CFS contains a recommendation that NES should work with ME-CFS organisations to develop training information for healthcare staff across Scotland.

(S3W-27237) **Jamie Stone:** To ask the Scottish Executive how many specialist treatment centres there are for myalgic encephalomyelitis, broken down by NHS board.

Nicola Sturgeon: Specialist services include a CFS/ME Nurse Specialist in NHS Fife. NHS Lothian maintains a specific, specialist diagnostic assessment and review clinic for people with ME-CFS. Access to this clinic is governed by a specific ME-CFS protocol that has been agreed with GPs. It is routinely available to them and facilitates GP referral to specialist services.

A Wellness Enhancement Learning Programme for people with ME-CFS has also been developed by the Centre for Integrative Care in Glasgow. We are funding an evaluation report on that programme to help promote its dissemination.

In order to encourage further progress in the development of services, we commissioned the Scottish Public Health Network (SPHN) to undertake a needs assessment for ME-CFS. The SPHN draft report provides further details of services at NHS board level (Appendix 5). It can be found at:

<http://www.healthscotland.com/resources/networks/scotphn/projects/CFSME.aspx>.

(S3W-27238) **Jamie Stone:** To ask the Scottish Executive how long the waiting list is for specialist myalgic encephalomyelitis treatment is in each NHS board.

Nicola Sturgeon: The information is not centrally available in the form requested. The diagnosis and treatment of ME is mainly undertaken in an outpatient setting. While outpatient waiting times information is centrally available for a first outpatient consultation, it is not possible to identify specific conditions such as ME, since the data are collected only at specialty level.

(S3W-27239) **Jamie Stone:** To ask the Scottish Executive how many myalgic encephalomyelitis specialists are employed by the NHS, broken down by NHS board.

Nicola Sturgeon: The information requested is not held centrally. The Scottish Public Health Network draft needs assessment for ME-CFS contains a recommendation that the specialist element of the service model it proposes (Tier 3) should consist of a multi-disciplinary team led by a Consultant in ME-CFS.

(S3W-27240) **Jamie Stone:** To ask the Scottish Executive what advice, in terms of options regarding employment, education or benefit entitlement, is offered to people with myalgic encephalomyelitis after initial diagnosis.

Nicola Sturgeon: People with ME-CFS are referred by GP practices to appropriate agencies such as the Department of Work and Pensions for information on benefit entitlement, to Job Centre Plus for advice and support on employment, to local authorities for education advice and to other relevant agencies such as Citizens' Advice Bureaux and voluntary sector organisations such as Action for ME.

(S3W-27241) **Jamie Stone:** To ask the Scottish Executive what information is available to people affected by a diagnosis of myalgic encephalomyelitis, such as employers and families of the person diagnosed.

Nicola Sturgeon: I refer the member to the answer to question S3W-27240 on 23 September 2009. All answers to written parliamentary questions are available on the Parliament's website, the search facility for which can be found at: <http://www.scottish.parliament.uk/Apps2/Business/PQA/Default.aspx>.

Information regarding ME is also provided by NHS 24 and voluntary organisations such as Action for ME.

MSPs can be e-mailed directly from the list at - www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Nicola STURGEON (SNP) Glasgow Govan

Nicola Sturgeon was a member of the Health Committee in the first session of the parliament, when the Cross Party Group on ME's petition was under consideration.

She supported the motion for debate in January 2002 and contributed to the debate as follows:

Nicola Sturgeon (Glasgow) (SNP): I join colleagues in congratulating Alex Fergusson on securing this important debate, which will be important in raising awareness about ME.

Susan Deacon was right to speak about the growing awareness of ME, but that should not mask the considerable ignorance that still exists in Scotland about the condition and its symptoms. ME sufferers do not simply experience fatigue. In general, they regularly experience many other symptoms, such as sore throats, muscle pains, headaches, disturbed sleep, digestive problems and depression.

There is also ignorance about the fact that the condition affects a great many people in Scotland—many more than are affected by higher profile conditions. In Scotland, some 15,000 people are thought to have ME. They include people of all ages, all social classes and men and women, although women are slightly more at risk than men.

The effects are severe. For young people, there can be disruption to education. There can be disruption to family life, work life and other serious effects. Despite that, and Scotland's history and record in medical research, we still do not have answers to basic questions—as Janis Hughes said. We do not know what ME actually is or who has it. There is no diagnostic test for it, as Fergus Ewing and Lord James Douglas-Hamilton rightly said. Diagnosis is still primarily done by excluding other conditions. That is not good enough.

Some members have rightly said that more research into the condition is needed. More publicly funded research is needed. Alex Fergusson said that there is expertise in Scotland. There is a need to carry out research here. We could engage in initiatives that would go a great deal of the way to beginning to find some answers to basic questions without involving an enormous investment of public resources.

Many members want to speak, so I will be brief. I am glad that the issue has united members and that the deputy minister can offer a positive contribution.

Nicola Sturgeon is the Minister for Health in the present administration, and in this capacity she has provided ministerial responses to several Parliamentary Questions on ME matters (see entries for Andy Kerr, Jamie Stone, Willie Coffey, and Mary Scanlon).

In common with other Ministers in the Scottish Government, she can be contacted in her Ministerial capacity at scottish.ministers@scotland.gsi.gov

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Jim TOLSON

(Liberal Democrat)

Dunfermline West

Jim Tolson asked this Parliamentary Question in 2008:

(S3W-11529) Jim Tolson: To ask the Scottish Executive what measures it is taking to promote the prioritisation of biomedical research into ME.

Shona Robison: The Chief Scientist Office (CSO) of the Scottish Government's Health Directorates has responsibility for encouraging and supporting research into health and health care needs in Scotland. The CSO does not commission research but supports research projects of a sufficiently high standard initiated by the research community in Scotland. This role is well known and advertised throughout the healthcare and academic community.

We are aware, through the work of ME Research UK, of the biomedical research which is being undertaken in relation to ME.

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www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

Sandra WHITE

(SNP)

Glasgow regional list

Sandra White supported both motions for debate on ME research - in 2002 and in 2005. She contributed to the 2005 debate (see below).

She was a member of the Petitions Committee in the second session of the Parliament, and a substitute member of the Heath Committee, so she may have some awareness of the passage of the Cross Party Group on ME's petition.

Sandra White attended the Cross Party Group's reception in 2005. In response to talk of the need to get clinicians interested in this area of work, she noted that this was not enough to ensure appropriate healthcare and spoke of the relevance of the political climate, with specific reference to the departure of Dr Chaudhuri from the Southern General Hospital, Glasgow (and the NHS in Scotland).

Ms Sandra White (Glasgow) (SNP): I congratulate Alex Fergusson on securing the debate. As Jean Turner said, his tenacity in pursuing the matter is most admirable. I have never seen anyone fight so much for something in the chamber or in a cross-party group. He obviously believes in the cause that he espouses.

Mike Watson mentioned something that I also want to pick up on, which is the fact that politics is being played by the medical profession in respect of ME. Doctors and professionals who do that should be ashamed of themselves and should think of patients rather than the medical profession. For the sake of the patients, they must stop playing politics with this issue.

I will read out just a few quotations from among the messages that I have received from people who suffer from ME:

"It is good to know that the MRC is giving some priority into research into ME."

"I would like money for research spent on looking into the physical causes of ME."

"There is an urgent need in my opinion that research be carried out".

"There needs to be research into the physical causes of this illness".

"There is a great need for better funding of research into the physical causes of this illness."

Alex Fergusson explained eloquently just how badly people are suffering. He and other members will have met constituents who suffer from ME and their carers, and will have tried to explain to them that although we in Parliament are doing our utmost, our calls are falling on deaf ears in the medical profession. Now, unfortunately, we must tell them that Scottish Enterprise, via the Scottish Executive, is also deaf to our calls. The situation is a sad one for me and people to whom I speak.

Every one of the quotations that I read out mentioned research, yet today we are talking about a team that is perhaps only one year away from finding a cure for ME being pulled apart because of lack of funding. The group originally contained Dr Chaudhuri, who is a fantastic champion for ME and has bashed away at the medical profession to convince them that research into the condition is needed. Unfortunately, we have lost Dr Chaudhuri. I appeal to the minister to ensure that funds are made available to enable research to continue. We must not lose any more researchers, as we lost Dr Chaudhuri. We must be able to say to our constituents and to people in Scotland who suffer from ME that we are prepared to allocate a couple of thousand pounds in order to see the research through in an attempt to find a cure.

MSPs can be e-mailed directly from the list at -
www.scottish.parliament.uk/apps2/msp/msphome/default.aspx : click on 'contact details'.

Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

David WHITTON (Labour)

Strathkelvin & Bearsden

David Whitton attended the Cross Party Group's Parliamentary Reception to mark ME Awareness Week in May 2010.

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Address for correspondence: The Scottish Parliament, Edinburgh EH99 1SP

John WILSON

(SNP)

Central Scotland regional list

John Wilson posed a number of Parliamentary Questions relating to ME in 2009:

(S3W-20629) John Wilson: To ask the Scottish Executive what information it has on how many people suffering from myalgic encephalopathy/chronic fatigue syndrome are recorded as unemployed.

Nicola Sturgeon: The data on CFS/ME collected by the Information Services Division of NHS National Services Scotland do not include details of people's employment status.

(S3W-20630) John Wilson: To ask the Scottish Executive what information it has on how many people suffering from myalgic encephalopathy/chronic fatigue syndrome are in receipt of incapacity benefit.

Nicola Sturgeon: The issue of incapacity benefit entitlement is a matter reserved to the UK Government and is the responsibility of the Department for Work and Pensions.

(S3W-20631) John Wilson: To ask the Scottish Executive how many people diagnosed with myalgic encephalopathy/chronic fatigue syndrome entered further or higher education in 2007-08, broken down by local authority area.

Nicola Sturgeon: The information requested is not available centrally.

(S3W-20632) John Wilson: To ask the Scottish Executive how many people were diagnosed with myalgic encephalopathy/chronic fatigue syndrome in the North Lanarkshire council area in each of the last five years.

Nicola Sturgeon: The information requested is not available centrally.