

10 YEAR CAMPAIGN FOR HEALTH CARE FOUNDED ON BIOMEDICAL RESEARCH

The Cross Party Group on ME was established in 2000

The aims of the petition are to:

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

2nd October 2001: **PETITION (398)** is presented to the Public Petitions Committee (PPC). Signatures: 17,721

Presenters:

- 3 speakers representing **CHILDREN / YOUNG PEOPLE and THE SEVERELY AFFECTED.**
- Alex Fergusson, MSP & Deputy Convenor of the CPG, speaks in support of the petition.

Response:

The Committee commends the speakers for the quality of their presentation. There is unanimous agreement that the aims of the petition are a matter of urgency.

Action

- PPC to seek the views of the Scottish Executive Health Department.
- Referral of the petition to the Health and Social Care Committee (H&SCC), seeking its views in respect of an inquiry.

23rd January: **DEBATE** on **RESEARCH** into ME .

Led by Alex Fergusson, Deputy Convenor of the CPG on ME.

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

- **16 MSPs speak in the debate – all in support of the motion.**

Closing remarks of Hugh Henry, Deputy Minister for Health:

“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”

8th February 2002: **SHORT LIFE WORKING GROUP** announced by Hugh Henry.

Aims

- **to consider the most effective ways of improving the care and quality of life for those with CFS/ME following the Working Group Report on CFS/ME of the Chief Medical Officer for England & Wales.**

CPG members are represented on the SLWG.

2002

December 2002: publication of

THE REPORT OF THE SHORT LIFE WORKING GROUP: *Outline for the Development of Services for CFS/ME in Scotland.*

RECOMMENDATIONS include:

- **NHS Boards to develop plans based on Needs Assessment.**
- **Tiered approach to services with different care pathways for the young; severely affected; house/bedbound and those in rural or remote areas.**
- **Provision of education and training to all professionals.**
- **Research.**

Action:

- **Scottish Executive Health Department to request all Health Boards to submit forward plans for services for ME/CFS.**

2003

Consideration of the **PETITION** is continued pending the reports from the Health Boards.

8th October: the Health Committee agrees

- **to seek comments from the petitioners and the CPG on ME regarding the SLWG Report, and**
- **to write to the Health Department about its plans to implement the recommendations of the Report.**

2004

13 January 2004: Health Committee

Alex Fergusson and Robin Harper attend to speak in support of the petition.

Key points:

- AF's correspondence from Health Boards suggests that the different approaches being taken will result in a piecemeal approach to health care services for ME.
- The petition's request for a **CENTRE OF EXCELLENCE** for treatment and **BIOMEDICAL RESEARCH** into ME continues to offer a solution to this problem.

Action

Dr Jean Turner, MSP, member of Health Committee, said:

“A heap of research is needed to find out what is going on in ME. If there were another condition that affected as many people as ME does, we would be trying to find out the cause.”

- Health Committee to write to Health Department asking when it expects to receive the Health Board progress reports on service development.

Outcome

- ❖ The HC's decision about the petition is deferred throughout the year pending the Scottish Executive's response on the progress reports from the Health Boards.

2005

1st February 2005: Health Committee

Alex Fergusson attends to speak in support of the **PETITION**.

Key points

- The length of time since the initiation of the Short Life Working Group – more than 2 years to date.
- The inadequacy with which the matter of ME is being treated by health boards – “a piecemeal and haphazard approach”.
- A lack of communication between health boards and patients contrary to the policy document *A New Public Involvement Structure for NHS Scotland: Patient Focus and Public Involvement*.
- In the previous 3 years the approach taken has done nothing to improve the lives of the estimated 20,000 ME sufferers in Scotland.
- The petition’s request for a **CENTRE OF EXCELLENCE**, whatever form that may take, continues to be a valid one.

Action

- The Committee agrees to delay closing the petition.
- The petition will be addressed in a special meeting with the Minister for Health and Community Care to address outstanding issues in respect of a number of petitions.
- The Committee anticipates that the petition will then be closed.

2005

2nd March 2005: The CPG hosts a **RECEPTION**.

Myalgic Encephalomyelitis (ME): The impact on sufferers: Is health policy in Scotland on the right path.

A briefing paper is circulated to all MSPs in advance.

MSPs and members of the group hear a number of presentations followed by a question and answer session:

- Alex Fergusson, convenor, describes the aim of providing MSPs with information to enable them to address and represent the needs of ME sufferers to Parliament and the Executive.
- Linda McLean speaks about the continuing severity of her daughter's ME and the lack of medical care.
- Dr Gregor Purdie gives a GP's perspective and describes the advantages of a **CENTRE OF EXCELLENCE**.
- Dr Vance Spence gives a presentation on issues surrounding **BIOMEDICAL RESEARCH** into ME.

2005

26th April 2005: Health Committee

Rhona Brankin, Deputy Minister for Health, attends to answer questions about progress on a number of petitions.

Key points raised:

- the length of the process to address the matters raised in the petition,
- the inadequacy of the current position of health boards
- the need for research.

Action

- Funding for a **NEEDS ASSESSMENT FOR CFS/ME** is announced.

Key remark by the HC

- The loss of time involved in the various strategies undertaken by the Scottish Executive before its acknowledgement of the requirement for a Needs Assessment.

Outcome

The Committee closes the **PETITION** following the announcement of the Needs Assessment.

- It recommends that the NA is initiated without delay.

The CPG produces a **LEGACY PAPER** which reaffirms and updates the aims of the group, including:

- The CPG's commitment to the establishment of a **CENTRE OF EXCELLENCE for ME** – a hub for all biomedical research and clinical care, incorporating the full spectrum of the condition.
- The need for funding to be directed at **BIOMEDICAL RESEARCH** instead of psychological management strategies.
- Clinical guidelines based on the **CLINICAL WORKING CASE DEFINITION, DIAGNOSTIC AND TREATMENT PROTOCOLS FOR ME/CFS** produced by Carruthers *et al* – the “Canadian definition”.
- The need for undergraduate **TRAINING AND CONTINUING PROFESSIONAL DEVELOPMENT** for all health professionals in the recognition and treatment of ME patients.

Developments

- The Health Department appoints the Scottish Public Health Network to carry out the **HEALTH CARE NEEDS ASSESSMENT FOR CFS/ME** which it announced in 2005.
- Action for ME (AfME), funded by the Health Department, publishes a **SCOPING EXERCISE** whose purpose is to inform the HCNA.
- The Health Department also funds AfME to produce guidelines for GPs – a **SCOTTISH GOOD PRACTICE STATEMENT FOR GPs (SGPS)**.

2008

During 2008, CPG members:

- Review several drafts of the **SCOTTISH GOOD PRACTICE STATEMENT FOR GPs.**
- Attend a stakeholder consultation arranged by the Scottish Public Health Network, commissioned to undertake the **HCNA for CFS/ME.**

2009

Developments

14th May: the launches take place of:

- The national consultation phase (until 9th September) of the **HEALTH CARE NEEDS ASSESSMENT FOR CFS/ME.**
- The final draft of the **SCOTTISH GOOD PRACTICE STATEMENT FOR GPs.**

The **SGPS** draft is subsequently put forward for review by medical professionals. Its final form is to be:

- The full SGPS as an online resource
- A quick reference guide for GPs
- A patient information leaflet.

2010

12 May:

The CPG marks **ME AWARENESS DAY** with a reception for MSPs.

Presentations:

- Update on the **HEALTH CARE NEEDS ASSESSMENT FOR CFS/ME.**
- Update on the **SCOTTISH GOOD PRACTICE STATEMENT FOR GPs.**
- **Linda McLean:** a family's experience of severe ME over the last ten years.

10 YEAR SUMMARY

In respect of the aims of the CPG's petition of 2001:

- The **HCNA** is nearing completion, 4 years after its announcement.
It does not include an assessment of needs of the most neglected patients: **severely affected and children / young people**.
- **GP** guidance on diagnosis and management is in the process of development.

The recommendations of **THE REPORT OF THE SHORT LIFE WORKING GROUP** of 2002 have not been delivered.

Petition aims still to be achieved:

- An epidemiological map of ME and CFS
- Accurate data on severely affected sufferers
- A **Centre of Excellence** for **biomedical research** and treatment.

These continue to be justifiable goals.

- In the 10 years of the CPG, the pace of progress towards effective health care for the full range of severity in ME sufferers has been too slow, hindered by the continuing debates about the nature of the illness.

To improve the development of health care for all ME sufferers:

- ✘ The problem of the gulf between biomedical and psychological explanations of ME – despite the evidence – must be resolved.

MSPS' SUPPORT TO ENABLE THIS DIALOGUE TO TAKE PLACE IS WELCOMED.