

# EUROPEAN PARLIAMENT

1999



2004

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*Session document*

FINAL  
**A5-0451/2003**

2 December 2003

## **REPORT**

on petition 842/2001 concerning the effects of discriminatory treatment afforded to persons with Multiple Sclerosis, within the European Union (2003/2173 (INI))

Committee on Petitions

Rapporteur: Uma Aaltonen



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## PROCEDURAL PAGE

On 15 October 2001 Petition 842/2001 by Louise McVay, on Multiple Sclerosis, was referred to the Committee on Petitions pursuant to Rule 174(5) of the Rules of Procedure.

At its meeting of 11 February 2002 the Committee on Petitions declared the petition admissible and decided at its meeting of 9 July 2003 to draw up a report pursuant to Rule 175(1).

It appointed Uma Aaltonen rapporteur at its meeting of 11 September 2003.

At the sitting of 4 September 2003 the President announced that the Committee on Petitions had been authorized to draw up a report under Rule 175(1) and that the Committee on Employment and Social Affairs had been asked for its opinion.

The Committee on Petitions considered the draft report at its meetings of 6 November 2003 and 27 November 2003.

At the last meeting it adopted the motion for a resolution unanimously.

The following took part in the vote, Vitaliano Gemelli (Chairman), Roy Perry, Proinsias De Rossa, Astrid Thors (Vice-Chairpersons), Uma Aaltonen (Draftsperson), Richard A. Balfe, María Luisa Bergaz Conesa, Felipe Camisón Asensio, Michael Cashman, Marie-Hélène Descamps, Christos Folias, Margot Keßler, Jean Lambert and Ioannis Marinos.

The opinion of the Committee on Employment and Social Affairs is attached.

The report was tabled on 2 December 2003 .

## MOTION FOR A EUROPEAN PARLIAMENT RESOLUTION

**on petition 842/2001 concerning the effects of discriminatory treatment afforded to persons with Multiple Sclerosis, within the European Union (2003/2173 (INI))**

*The European Parliament,*

- having regard to Petition 842/2001 by Ms Louise McVay,
  - having regard to Rule 175,1 of its Rules of Procedure,
  - having regard to the report of the Committee on Petitions and the opinion of the Committee on Employment and Social Affairs.(A5-0451/2003),
- A. Whereas the Charter of Fundamental Rights of the European Union declares that human dignity is inviolable and that it must be respected and protected;
- B. Whereas Article 26 of the same Charter states that " The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."
- C. Bearing in mind that Article 35 of the Charter places medical treatment under the responsibility of national laws and practices, although the Union must ensure a high level of human health protection in the definition and implementation of its policies and activities;
- D. Whereas Article 152(1) of the EC Treaty confirms that "a high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities", thus requiring the integration of health concerns in Community decision making whenever this might be called for;
- E. Whereas Article 152(2) lays down that "Community action, which shall complement national policies, shall be directed towards improving public health, preventing diseases, and obviating sources of danger to human health"; whereas pursuant to Article 152(3) "the Community and the Member States shall foster cooperation with third countries and the competent international organisations in the sphere of public health";
- F. Considering that persons with Multiple Sclerosis, and many other chronic long-term illnesses, are subject to varying levels of medical and therapeutic care depending on their place of residence and that insufficient priority has been accorded by Member States of the Union, as well as by the Institutions of the European Union, to remedying this fact;

- G. Whereas in recent years there has been considerable progress achieved, through scientific and medical research into Multiple Sclerosis, with the provision of drug treatments which reduce the disability of MS patients, as well as the provision of medicines for symptom relief;
- H. Whereas the causes of Multiple Sclerosis remain largely unknown, although it is believed to result from a combination of genetic, environmental and immunological factors; whereas, therefore, research into the causes ought to encompass, and seek to inter-relate such different potential elements;
- I. Regrets that access to such medicines remains unequal within Member States of the European Union for budgetary reasons or because of insufficient attention being paid to the problem by health authorities, and that the effects of this situation are aggravated due to the need to administer effective medication at the earliest stage possible following diagnosis to ensure the best results;
- J. Whereas within the European Union there are currently some 400,000 persons who have been diagnosed with Multiple Sclerosis according to the European Multiple Sclerosis Platform, and that MS is the most common cause of disability affecting young adults of which two out of three are women;
- K. Bearing in mind the need, beyond drug therapy, to develop effective and properly resourced services in care for Multiple Sclerosis patients which address their complex and life long requirements
- L. Recognising that the European Union has acted to ensure better employment prospects for disabled persons generally through the Directive on Equal Treatment in the Workplace, but that the full and effective implementation of this Directive will take a long time unless national and local authorities act with greater resolve to encourage employers to fulfil their responsibilities towards such vulnerable persons;
- M. Whereas there is a demand for a more comprehensive Disability Rights Directive and that a draft for this Directive has been prepared by representatives of disabled persons and lawyers and promoted by the Disability Intergroup of the European Parliament; whereas adequate implementation of measures already adopted on the basis of Article 13 of the EC Treaty remains an equally important priority;
- N. Bearing in mind the Public Health Action Programme of the European Union (2003 - 2008) and the encouragement this provides for health service professionals and public bodies to devise more coherent health strategies for dealing with such diseases as Multiple Sclerosis on a Europe-wide basis;
- O. Whereas it is essential to enhance the financial resources available for research into Multiple Sclerosis within the European Union as well as improving the complementarity of research projects given the combination of factors that are said to trigger the disease;

- P. Whereas concerns have been raised about possible connections between Multiple Sclerosis and exposure to toxic chemicals;
- Q. Whereas closer international cooperation is vital to capture more targeted funding in the field of genetics, research and studies into autoimmune diseases, and, thus, in order to advance efficiently in the development of the understanding of Multiple Sclerosis, as well as in the development of therapies and treatments;
- R. Affirming that the restriction of access to effective therapies and disease modifying drugs not only impacts disastrously on an individual's ability to work, on his or her family life, freedom of movement and integration into society in general, but is also a denial of basic rights;
- S. Considering that people with Multiple Sclerosis are frequently disappointed with the level of understanding and expertise of health care professionals who deal with their problems, and that a more positive approach is often required towards them which concentrates also on what they can achieve as individuals rather than focusing exclusively on their problems;
- T. Whereas, given the large numbers of relatively young people who have to live with MS, there are in most EU countries very few nursing homes or day-care facilities which cater for their needs as they are frequently obliged to share accommodation with elderly or geriatric patients, which is neither convenient nor socially suitable for either;
- U. Considering that the securing of best practice for equal access to therapies and treatments and better services for people with Multiple Sclerosis should become a principal objective to be obtained by all health authorities in the European Union, and that each Member State should encourage its partners in this course of action through co-ordinated programmes designed in conjunction with the World Health Organisation;
- V. Recognising and paying tribute to the crucial role played by national Multiple Sclerosis Societies and the European Multiple Sclerosis Platform in securing real improvements for persons with MS, through their commitment to finding solutions to the many problems faced by individuals, and through their constant efforts to influence policy makers and practitioners in a way which is conducive to finding remedies;
- W. Noting in particular their role in the provision and dissemination of useful and essential information for persons with Multiple Sclerosis, which in turn may provide comfort, support and real solidarity for many persons who otherwise might find themselves even more isolated from issues and debates which concern them directly;
1. Calls upon the European Commission to specifically itemise a discussion to address the issues raised in this report on Multiple Sclerosis at a forthcoming meeting of

Ministers of Health of the European Union with a view to developing a "Code of Best Practice" to be followed in all Member States;

2. Urges the Commission to develop closer international scientific collaboration, in the context of the 6<sup>th</sup> & 7<sup>th</sup> Framework Programme of Research, in order to accelerate the development of even more effective treatment of Multiple Sclerosis in all its forms;
3. Notes that nevertheless, the root causes of MS, which affects more than 400,000 EU citizens, are still unknown and that the Sixth Research Framework Programme has not lived up to the commitment to "mainstream" disability issues - the level of EU research relevant to disability and conditions such as MS has in fact dropped off; insists that this be prioritised in the Seventh Research Framework Programme;
4. Believes that such research should involve service users in order to ensure that efforts are properly directed towards the needs of persons affected by Multiple Sclerosis;
5. Recalls the concept of the "reasonable accommodation" of disabled people's needs in Directive 2000/78/EC on equal treatment in employment and urges Member States to implement the terms of the Directive in full by the deadline of 3 December 2003;
6. Calls for an urgent Europe-wide epidemiological study to be conducted and financed by the European Union, in cooperation with the WHO, in order to collect relevant data which could contribute to research into the clarification of the causes of Multiple Sclerosis, which remain to this day, unknown;
7. Welcomes, in this context, the current comparative evaluation being undertaken into the management of certain European Multiple Sclerosis Centres in order to evaluate quality and verify the implementation of good practices, which will lead to the development of positive 'benchmarks' and the identification of integrated care pathways and rehabilitation activities;
8. Urges Member States and the European Commission to recognise and endorse the view that the cost-effectiveness of drug therapies used for patients with Multiple Sclerosis and other long-term chronic diseases should be measured not only through clinical trials, but also through an assessment of improvement in the quality of life afforded by new treatment which could have positive implications for savings in other sectors of social or welfare budgets;
9. Believes that persons with Multiple Sclerosis should be actively encouraged and invited to participate in the development of programmes, alongside medical practitioners and other professional advisers;
10. Calls upon the European Commission and the Health Authorities in the Member States to support and promote user-led self management courses for people with MS and other long-term conditions in order to enable them to be in a better position to access appropriate therapies and manage as far as possible their own health condition;

11. Urges the Member States of the EU to promote the development of specialised clinics and nursing homes designed to respond to the needs of younger persons with Multiple Sclerosis who require institutional care because of their particular situation, and to recognise the importance of such matters in the current organisation of hospital or nursing facilities;
12. Supports a right to independent living for people with MS and other disabilities, which involves the provision of timely and appropriate health and social care, in order to respect personal dignity and autonomy;
13. Believes that greater incentives should be available to encourage the professional training of neurologists, specialist nursing staff and other health-care practitioners to enable them to specialise in developing and administering the most effective treatment and therapies for persons with Multiple Sclerosis; and believes that such efforts should ensure a wider positive impact on MS patients throughout the European Union;
14. Encourages much closer international cooperation, - indeed this is vital to capture more targeted funding, notably through contacts with other countries where advanced research is conducted, in the field of genetics, and other causal factors of Multiple Sclerosis as well as related studies into other autoimmune diseases;
15. Calls upon the European Commission, in cooperation with the Member States to devise and implement framework legislation which privileges job-retention for persons with Multiple Sclerosis, many of whom are currently coerced into giving up work against their will, even though studies have shown the positive mental effects of continued work which can reduce the progression of the disease;
16. Recommends enhanced measures are taken to promote the employment of disabled people which must:
  - raise awareness, amongst employers and co-workers, about the reality of disabilities and conditions such as MS and their impact;
  - respect the individual nature of conditions like MS;
  - be evaluated so as to feed into exchanges of ideas and experiences, particularly at EU level, which should help develop and spread successful models for the benefit of all;
17. Requests that local and national authorities develop the built environment much more to facilitate access to buildings and transport for people with MS, and similar illnesses, using uniform access standards;
18. Underlines that access by people with MS and other disabilities cannot be achieved by removing environmental/physical barriers alone, but involves breaking down all obstacles which inhibit equal access to goods and services;
19. Requests the European Commission to submit a proposal for a comprehensive Disability Rights Directive using the proposals promoted by the European Parliament's Disability Inter-group as a basis;

20. Instructs its President to forward this resolution to the Commission, Council, the World Health Organisation and to the petitioner.

## EXPLANATORY STATEMENT

IMPORTANT NOTICE: THIS IS A PARLIAMENTARY REPORT NOT A CLINICAL OR SCIENTIFIC DOCUMENT AND ALTHOUGH GREAT CARE HAS BEEN TAKEN IN ITS PREPARATION COMMENTS ON THE MEDICAL ASPECTS OF MS SHOULD BE READ WITH APPROPRIATE CAUTION.

In August 2001, Louise McVay addressed a letter to the President of the European Parliament concerning the disparity of treatment afforded by EU countries to persons who have been diagnosed with Multiple Sclerosis. Moreover such disparity, she pointed out, was frequently devolved even within certain countries - in her case the United Kingdom - so that access to essential medicines for treating the disease became dependant on what was described by the petitioner, and others, as a "post-code lottery".

The problems encountered by someone with MS of course neither begin, nor end with access to necessary and essential medical treatment. Difficulties are encountered at many other levels, from the personal and psychological impact of being diagnosed with the disease to the occupational and professional impact on a person's life and the corresponding threat to their income and material well being.

The petitioner appealed to the European Parliament, as she said "in desperation", in order to try to obtain some recognition not only for her personal situation, but more importantly as she also said for the thousands of other people who were suffering from such inequality of treatment, many of whom are still being denied their fundamental human rights of access to proper medical support.

The Committee on Petitions as its procedures provide for, requested the European Commission to look into the matter before deciding what other follow-up actions could be envisaged. The Commission response, dated April 2002 was disappointing because it merely informed the Committee that this matter was nothing to do with European law, but was the sole competence of the Member States.

The Committee decided that it would have been short-sighted and morally wrong to simply abdicate its responsibility to many thousands of European citizens who are all looking for answers to such questions. Louise McVay was invited to make her case before the Committee which she did most eloquently on July 9th 2003. Also present were the European Multiple Sclerosis Platform and the MS Societies from Italy Belgium Germany and the UK as well as MS sufferers from several other European countries. It was as a result of this debate that the Committee decided to draw up a Report, in close cooperation with the Committee on Employment and Social Affairs, in order to provide a clear set of answers for Louise McVay and also to set out what it believes to be a clear and necessary European strategy for combating this debilitating disease for which, at this time, there is still no known cure.

### **Multiple Sclerosis: the nature of the disease.**

Multiple Sclerosis is an inflammatory disease of the central nervous system and the nerve fibres themselves, which progressively develop lesions which then prevent the nerve from functioning, causing a widespread and unpredictable level of disability. Partial or complete

loss of body functions can develop as a result of a degeneration of the nerve fibres. People are affected to different degrees with a variable evolution over time. It is an autoimmune related disease and thus has some common characteristics with other autoimmune diseases. Early diagnosis and treatment with designated drugs (Betaferon, Avonex, Copaxone, Rebif (Serono Beta interferon 1a) 22mg & 44mg and Glatiramer acetate) which have been marketed only in the relatively recent period can make an enormous difference to individual sufferers to such an extent that they are really life enhancing.

There are four main categories of Multiple Sclerosis:

- Relapsing/Remitting (RRMS),
- Secondary Progressive (SPMS),
- Progressive Relapsing (PRMS) and
- Primary Progressive (PPMS).

These have been defined within the last twenty years as research has advanced into the understanding of the disease. The medical treatment and therapies available are related to the specific category of MS contracted by a patient.

The above-mentioned drug treatments are however, only suitable for those with RRMS and SPMS, in other words only about a quarter of those with Multiple Sclerosis. Most persons with MS will require different forms of drug treatment to deal with the many symptoms of the illness - fatigue, spasticity, pain, impotence, incontinence or depression. For acute attacks corticosteroids may be required. Recent research has investigated the use of cannabinoids as a treatment for many symptoms, though the results remain inconclusive. They do indicate however that patients derived a significant benefit from taking orally administered doses in terms of pain relief and a reduction of discomfort during walking. The researchers speculate that "cannabinoids might have a more specific role in the management of chronic neuropathic pain." (The Lancet, November 2003 - Zajicek et al, UKMS Research Group)

Within the last decade neurologists have grown to better understand the way in which the nervous system becomes damaged and how the symptoms are produced. (*See ref: Multiple Sclerosis, The Guide to Treatment and Management, published by the MSIF*) The improvements in magnetic resonance techniques (in particular, brain scans) have also greatly contributed to the analysis and understanding of MS. However the cause of the disease is still not fully understood, although it is believed to result from a combination of genetic, environmental and immunological factors. 'Stressful life events' have also been identified by some researchers as a factor in provoking the onset or increasing the exacerbations in RRMS. But it often takes several years to diagnose Multiple Sclerosis and there are, as has been noted above, different variations of the disease. However, the more widespread use of magnetic resonance imaging has meant that, nowadays, a diagnostic can be made earlier in many cases.

The personal trauma for any individual who is diagnosed with MS is obviously considerable as it affects every aspect of their daily lives, and any effective therapy must allow for professional counselling. Yet, it is also important to realise that the impact of MS resonates on the person's immediate personal and social environment and often their professional responsibilities as well. That is why, as for other serious ailments and diseases, the response from governments, health authorities and where applicable EU institutions and international bodies, must relate to the individual therapy (medical treatment, nursing and hospitalisation,

long-term care), as well as the broader macro-environment of the person with MS (research into the disease, employment rights, carers' rights, transport facilities, free movement, cross-border medical assistance and so on). At every level priority must be given to the integrity of the person with MS and the choices that each individual must make about their lives.

### **Epidemiological considerations.**

The 'Fondation Charcot' in Belgium has published a fascinating study on the subject which includes a general epidemiological survey of MS prevalence. One hypothesis which is ventured suggests that MS originated among the Viking population of Northern Europe in the VIII and IX century and its current geographical distribution globally reflects migration patterns from this source since then.

They sketch the areas of the world where evidence of the illness is the most preponderant. Such areas include Northern Europe - but also Italy, the United States and Canada as well as Australia and New Zealand. Within the European area, the Orkney & Shetland Isles have the highest level of prevalence. It is interesting to note that in the US, the population most affected is of Scandinavian origin.

The study emphasises of course that genetic background is but one variable in a very complex clinical range which may one day allow the scientific community to identify more clearly the causes of Multiple Sclerosis. A molecular genetic study on a global scale would be required to provide clear evidence in relation to the apparent origin of the disease. At the same time, it is also indicated that in France for example, genetic factors appear to be much less important compared to other external factors of possible causes for the triggering of the disease.

Other possible causal factors, including even environmental ones, also need to be more comprehensively assessed and potential correlations established because even though the genetic element is of great interest, it is clear that a multiplicity of elements are involved at the genesis.

### **The situation in some Member States.**

In the UK, there is a greater prevalence of Multiple Sclerosis in Scotland and Northern Ireland than in England and Wales. One general hypothesis which is gaining in credence, related to this and to the epidemiological pointers mentioned above is that there is an underlying genetic predisposition to the contracting of the disease. About 85,000 people have Multiple Sclerosis in the United Kingdom.

The United Kingdom government, through the Department of Health, issued a circular to all Health Authorities in 2002 which was designed to remedy some of the complaints to which Louise McVay's petition referred. It was concerned with "Cost Effective Provision of Disease Modifying Therapies for People with Multiple Sclerosis" and behind the 'cost-effective' banner it explained how MS patients could participate in the new scheme. "All patients with relapsing-remitting MS, and those with secondary progressive MS in which relapses are the dominant clinical feature, who meet the criteria developed by the ABN (*Association of British Neurologists*) are eligible for treatment under this scheme."

This represented a big step forward though it has not managed to resolve the therapy-related problems experienced by the majority of MS sufferers even today. Indeed, the circular admits that the total number of patients in England and Wales who fall within its guidelines may only be within the range of 12% - 15% of patients with MS – 7,500 to 9,000 people.

The Office for Public Health in Scotland has published a most valuable and comprehensive "Needs Assessment Programme" which makes a number of highly important proposals for dealing with the effects of the disease. Interestingly, this report allows itself to suggest what the "ideal MS service" should do:

- allow rapid referral of suspected cases
- provide assessment of possible diagnosis by neurologist
- provide assessment from a multi-disciplinary team experienced in MS management to identify individual needs and to deliver appropriate service
- provide ongoing and continuous follow-up at defined intervals and also to allow a rapid self-referral system at times of crisis
- provide information and support to patients and carers.

Such a model has clear value at the European level. However, the report also emphasises that wide variations in accessibility and quality of care exist and that current care is "substantially sub-optimal".

As in many other countries in Europe there is a problem for younger people who are more seriously affected by the disease and who require treatment in nursing homes or other medical institutions. Very often such care centres are catering more for elderly or geriatric patients and this causes additional problems of care which may be ill suited in such circumstances.

In Belgium MS sufferers have identified this as a major problem as nursing homes are ill adapted for young people, and the specificity of their requirements may be consequently neglected. There is also a severe shortage of housing generally for MS patients, many of whom could remain more independent if suitable accommodation were to be found, and more support facilities available in terms of home assistance, security, possibilities of short-term care when needed and so on.

In Finland there are about 6,000 people diagnosed with MS from a population of 5.2 million. For these persons specialised health case treatment is available in 21 district and 20 central hospitals, where multi-disciplinary teams are located - five of these are university based. Finland's biggest cities also have multi-disciplinary teams in health case centres. Neurological rehabilitation centres, such as the one in Masku aim to improve and maintain an MS patient's abilities to work and cope in society, while providing family support. National guidelines are established and a 'best practice' programme initiated for dealing with MS. Many details have been provided to me by the Finnish Minister of Social Affairs and Health in reply to my letter (see Annex) and it is also important to add that there is already a high level of cooperation between Scandinavian countries in this field.

This is echoed by Denmark's Minister for the Interior and Health who suggests specifically in reply to my letter that the EU could support the establishment of a European Network of MS Research Centres in order to facilitate MS research. Austria has also made some suggestions

in this direction considering also that the EU could sponsor multi-disciplinary MS clinics.

In France, there are estimated to be between 50,000 and 60,000 persons with Multiple Sclerosis. The health authorities have developed a network of MS specialised centres in several main cities.

Germany is the country in Europe which numerically is estimated to have the largest number of persons with MS though its population size is also the largest as we know. Approximately 100,000 people have the disease. However, outside the activities proposed by the MS society (DMSG) there does not appear to be a very comprehensive approach adopted by the national or regional authorities to manage the disease and its implications.

Denmark, on the other hand, appears to be one of the most advanced amongst the European countries in its approach to the disease, though much is dependent on the MS society itself. Some 6,000 persons have Multiple Sclerosis in the country and treatment prescribed by neurological departments of hospitals which are located in all parts of the country is free.

In the employment field the opportunities for persons with MS to find work is facilitated by the system of "Flexjob", where a person can work basically a half-time period of 18 1/2 hours per week on full pay, with the government picking up the tab for the half-time period. Days off work may then be spent for physiotherapy, which is free, and so on. There is also financial support for transport, housing facilities and other expenses caused by the handicap.

As with other countries however, there is a problem in the provision of suitable long term accommodation and housing for younger persons with MS.

In Italy, there are 52,000 persons with Multiple Sclerosis. The highest prevalence of the disease is to be found in Sardinia, which has more than twice the national average (200 per 100,000 inhabitants.) Some 14,000 persons with relapsing remitting and secondary progressive MS receive immunomodulating drugs on the national health.

There are two hundred neurological centres with about six hundred neurologists prescribing and distributing such life enhancing drugs to patients. Only eight per cent of the centres however provide an interdisciplinary approach to Multiple Sclerosis treatment and no specialised long-term care is available. The Italian MS Society itself provides some social and rehabilitation centres as well as some home help services.

Regarding other countries, further details will be given in a revised draft, but numerically the prevalence of MS is as follows: Sweden: 12,000, Portugal: 6,000, Netherlands: 15,000, Austria: 8,000, Greece: 5,000, Spain: 30,000, Luxembourg: 400, and Ireland: 4,000

## **Conclusions**

Multiple Sclerosis is of course but one of a growing number of diseases of the autoimmune system which affects an increasing number of European citizens, and for which a cure must one day be found. Most people who have never met anyone with MS may be forgiven for not paying much attention to the subject, as we all have enough to be concerned about in our daily lives.

Yet, our public authorities at national and European level do not, of course, have that excuse. Indeed they have a clear responsibility and an obligation towards their citizens' health requirements and well-being. In general this responsibility is properly fulfilled by the provision of health care to the greatest number of persons possible, and Europe is in fact rather unique for having adopted such an inclusive approach to health care generally compared to other continents.

At the same time, it would appear that as regards Multiple Sclerosis, the European Institutions could play a more effective rôle in promoting greater collaboration between Member States in the fight against this pernicious disease. If this is not done at the moment it is probably not because of a lack of will, but because of a lack of awareness of the problem and what is required to remedy it. Resources are generally too scarce in every member state to manage every competing demand on health issues which arise, (and governments set their own priorities) which is why much more emphasis must be placed on collaborative efforts between member states and their specialists, with the European Commission playing a useful coordinating and initiating function. It is to be hoped that some of the strategic proposals contained in this report might help with that.

Multiple Sclerosis, as we have demonstrated, is a complex disease to understand and it represents a bigger challenge to deal with because of its progressive nature and because of the fact that those affected are generally young and in their prime of life. At a time when they would normally be expected to be at their most productive they are instead confronted with an uncertain future in their family and professional lives. For this reason it deserves, and must obtain, much greater recognition and consequently public authorities must place a greater priority on finding meaningful solutions to the various types of difficulties encountered by those with Multiple Sclerosis.

Some are relatively fortunate in their access to treatment and therapy. But the disparities between the types of care and support available are much too great both within and between the member states of the Union. This must be remedied by raising the level of care provided across the board, bringing about equality of access as a clear objective. With free movement of persons recognised as a binding principle of the Union, better provisions must be put in place to enable the disabled person, including MS sufferers, with equal rights to treatment in all EU states.

This report has tried, amongst other things, to conduct an objective assessment of the situation using Louise McVay's petition as its starting point, but there are many gaps, which is also why a number of specific suggestions for further collaborative efforts have been proposed in the resolution section. The European Parliament will also continue to pursue the matter through its own channels and structures with vigour and determination.

Dear Minister,

I have recently been appointed by the Committee on Petitions of the European Parliament as their Rapporteur, with the responsibility of preparing a report on "**Multiple Sclerosis and its treatment in the different Member States of the European Union.**" It is the intention of the Parliament to debate this issue when it holds its last plenary session of the year in Strasbourg in the week of December 15th. I am therefore obliged to work with considerable speed and I would be most grateful for your cooperation regarding the provision of information to assist with factual presentation of my report.

My report will not be of great length, given the time available, but it must reflect as accurately as possible the current efforts which EU Member States are making to provide treatment and other forms of support for MS sufferers. It would be of particular help if you could provide me with an answer to the following points, although I would gratefully accept any useful information which you might think pertinent, naturally in your own official language version.

- What means of access are available to MS sufferers for disease modifying drugs & therapy?
- How many neurologists/consultants are registered as MS specialists in your country?
- How many multi-disciplinary medical teams are available and where are they located?
- What level of expenditure (public and/or private) is there for MS-related research?
- Are there specific provisions for the long-term care of MS patients?
- Have you conducted an epidemiological study into Multiple Sclerosis?
- What "best practices" does your country have to offer MS patients?
- What could/should the EU do to assist in fighting this disease -research, social/employment legislation, facilitation of Europe-wide cooperation between Member States etc?

I realise as an MS sufferer myself, that such questions may be difficult to respond to especially as if possible I would much appreciate a reply by November 6th, when the Petitions Committee will be having a detailed exchange of views on the subjects. Of course, representatives from your Ministry or your Permanent Representation in Brussels would be most welcome to attend.

Thank you so much for your cooperation and assistance with this matter,  
Yours sincerely

Uma Aaltonen MEP.



26 November 2003

## **OPINION OF OF THE COMMITTEE ON EMPLOYMENT AND SOCIAL AFFAIRS**

for the Committee on Petitions

on petition 842/2001 concerning the effects of discriminatory treatment afforded to persons with Multiple Sclerosis, within the European Union (2003/2173(INI))

Draftsperson: Richard Howitt

### **PROCEDURE**

The Committee on Employment and Social Affairs appointed Richard Howitt draftsperson at its meeting of 9 July 2003.

It considered the draft opinion at its meetings of 3 November 2003 and 26 November 2003.

At the latter meeting it adopted the following suggestions unanimously.

The following were present for the vote: Theodorus J.J. Bouwman, chairperson; Richard Howitt, draftsperson; Jan Andersson, Elspeth Attwooll, Regina Bastos, Ieke van den Burg, Philip Bushill-Matthews, Proinsias De Rossa, Harald Ettl, Carlo Fatuzzo, Ilda Figueiredo, Fiorella Ghilardotti (for Enrico Boselli), Anne-Karin Glase, Robert Goebbels (for Alejandro Cercas), Stephen Hughes, Rodi Kratsa-Tsagaropoulou, Arlette Laguiller, Elizabeth Lynne, Thomas Mann, Claude Moraes, Manuel Pérez Álvarez, Bartho Pronk, Lennart Sacrédeus, Elisabeth Schroedter (for Jillian Evans), Miet Smet, Helle Thorning-Schmidt, Anne E.M. Van Lancker and Barbara Weiler.

## SUGGESTIONS

The Committee on Employment and Social Affairs calls on the Committee on Petitions, as the committee responsible, to incorporate the following suggestions in its motion for a resolution:

1. Supports the work of representative organisations of people with Multiple Sclerosis (MS) in their fight for equal access to treatment and services, within the "social model" of disability which seeks to promote societal change to eliminate discrimination against all people with disabilities;
2. Expresses grave concern at the denial of healthcare to people with disabilities in Europe in many instances, which represents a fundamental breach of their human rights;
3. Notes that the root causes of MS, which affects more than 400,000 EU citizens, are still unknown and calls for more and better co-ordinated research at national, European and world-wide level; also notes that the Sixth Research Framework Programme has not lived up to the commitment to "mainstream" disability issues and that the level of EU research relevant to disability and conditions such as MS has in fact dropped off; insists that this be rectified in the Seventh Research Framework Programme;
4. Recalls that discrimination in the provision of healthcare is included in the Council Directive 2000/43/EC implementing the principle of equal treatment between persons irrespective of racial or ethnic origin<sup>1</sup> (based on Article 13 TEC) and insists that such healthcare-related discrimination against people with MS strengthens the case for a comprehensive non-discrimination directive on disability;
5. Recalls the concept of the "reasonable accommodation" of disabled people's needs in Directive 2000/78/EC on equal treatment in employment and urges Member States to implement the terms of the Directive in full by the deadline of 2 December 2003;
6. Underlines that access by people with MS and other disabilities cannot be achieved by removing environmental/physical barriers alone, but involves breaking down all obstacles which inhibit equal access to goods and services;
7. Supports a right to independent living for people with MS and other disabilities, which involves the provision of timely and appropriate health and social care, in order to respect personal dignity and autonomy;
8. Notes that people affected by MS often have invisible and intermittent symptoms (such as fatigue or incontinence) and that, like people with other invisible disabilities, their concerns are often not recognised or taken seriously;
9. Is concerned that, due to misperceptions and discrimination by employers and other factors, 50% of people with MS are no longer in work 5-7 years after diagnosis, rising to two-thirds within 15 years of the onset of symptoms;
10. Emphasises the economic, social, psychological and therapeutic importance of a

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<sup>1</sup> OJ L 180, 19.7.2000, p. 22

working life for people with MS who, like people with other disabilities, are keen to work and develop professionally;

11. Supports enhanced measures to promote the employment of disabled people which must:
  - raise awareness, amongst employers and co-workers, about the reality of disabilities and conditions such as MS and their impact;
  - respect the individual nature of conditions like MS, which affects each person differently, involving a range of symptoms experienced with varying degrees of severity/frequency;
  - place the person concerned at the centre - in line with the more general emphasis in the EU Employment Strategy on individual, personalised labour market measures;
  - be broad in scope, covering everything from the physical work place and transport, through working time and rest models, to assistive technologies and job counselling; and
  - be evaluated so as to feed into exchanges of ideas and experiences, including at EU level, which should help develop and spread successful models for the benefit of all;
  
12. Recognises that social security spending priorities are for Member States to decide but nevertheless regrets the unfairness of the situation whereby people with the same symptoms can have radically different entitlements and treatment in different countries; contends that, in some parts of the EU, the failure even to recognise the condition and to reflect its variability represents a double discrimination, given that MS disproportionately affects women.