


Procedure file

Basic information		
INI - Own-initiative procedure	2003/2173(INI)	Procedure completed
Effects of discriminatory health care to persons with multiple sclerosis in the Union. Petition 842/2001		
Subject 4.20.01 Medicine, diseases		

Key players			
European Parliament	Committee responsible	Rapporteur	Appointed
	PETI Petitions		11/09/2003
		V/ALE AALTONEN Uma	
	Committee for opinion	Rapporteur for opinion	Appointed
	EMPL Employment and Social Affairs		09/07/2003
		PSE HOWITT Richard	
ENVI Environment, Public Health, Consumer Policy	The committee decided not to give an opinion.		

Key events			
04/09/2003	Committee referral announced in Parliament		
27/11/2003	Vote in committee		Summary
27/11/2003	Committee report tabled for plenary	A5-0451/2003	
18/12/2003	Debate in Parliament		
18/12/2003	Decision by Parliament	T5-0601/2003	Summary
18/12/2003	End of procedure in Parliament		

Technical information	
Procedure reference	2003/2173(INI)
Procedure type	INI - Own-initiative procedure
Procedure subtype	Initiative
Legal basis	Rules of Procedure EP 227-p2
Stage reached in procedure	Procedure completed
Committee dossier	PETI/5/20054

Documentation gateway					
Committee report tabled for plenary, single reading		A5-0451/2003	27/11/2003	EP	
Text adopted by Parliament, single reading		T5-0601/2003 OJ C 091 15.04.2004, p. 0528-0683 E	18/12/2003	EP	Summary

Effects of discriminatory health care to persons with multiple sclerosis in the Union. Petition 842/2001

The committee adopted the own-initiative report by Uma AALTONEN (Greens/EFA, FIN) on a petition (840/201) on the effects of discriminatory treatment afforded to multiple sclerosis (MS) sufferers within the EU. The report pointed out that over the last 20 years considerable progress had been made in understanding MS and in ways of detecting it early and improving the quality of life of sufferers, provided that they had access financially and technically to the necessary treatment. In practice, however, this was not always the case, as the petition, submitted by an MS sufferer, had made clear: the treatment available to sufferers could vary depending on their Member State and even within Member States. Disparities could exist in access to medicine, medical refunds or any psychological, financial or other aid a sufferer may need. Patients were far too often simply left to cope with their physical and mental distress. MEPs deplored this situation and said that a "principal objective" of the health authorities in the EU should be to guarantee equal access to therapies and treatments as well as the provision of optimum services, through coordinated programmes drawn up in conjunction with the World Health Organisation. The committee wanted a debate on this subject to be placed on the agenda of a forthcoming meeting of EU Health Ministers, and also called for an epidemiological study funded by the EU to be carried out as a matter of urgency Europe-wide. In addition, the committee wanted the Member States to develop specialist clinics and nursing homes designed to meet the specific needs of sufferers, in particular younger ones, as well as the necessary professional training for medical and hospital staff. It stressed that the cost-effectiveness of drug therapies for sufferers of MS and other long-term chronic diseases should be measured not only through clinical trials but also through an assessment of the improvement in the quality of life as a result of new treatment, which could help bring about savings in other sectors of social or welfare budgets. MEPs also underlined the need to foster advanced research in this field through international cooperation, in the field of genetics and other areas. They further recommended that MS sufferers be integrated into the world of work by means of practical provisions that take account of their condition (including better access to buildings and transport), so that they can become as independent as possible. MEPs emphasised that many sufferers were currently coerced into giving up work against their will, even though studies had shown that continued work had positive mental effects which could reduce the progression of the disease. Lastly, they called on the Commission to put forward a proposal for a comprehensive Disability Rights Directive on the basis of proposals made by Parliament's Disability Inter-Group. ?

Effects of discriminatory health care to persons with multiple sclerosis in the Union. Petition 842/2001

The European Parliament adopted a draft own-initiative resolution drafted by Uma AALTONEN (Greens/EFA, FIN) on the discrimination to which Europe's multiple sclerosis sufferers are subject as regards health care, depending on their nationality with 340 votes in favour, 0 against and 4 abstentions. Multiple sclerosis is a debilitating and unpredictable illness. The Commission is urged to develop closer international scientific collaboration, in the context of the Sixth and Seventh Framework Programmes, in order to accelerate the development of even more effective treatment of multiple sclerosis in all its forms. 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 decreased. It insists that this be prioritised in the Seventh Research Framework Programme. Over the last twenty years important progress has been made in understanding this illness and in ways of detecting it early and improving the quality of life of sufferers, provided of course that they can have access financially and technically to the necessary treatment. In practice, this is not always the case, as was pointed out to MEPs in a petition (840/201) by a multiple sclerosis sufferer, Louise McVay. She explained how much the treatment available to sufferers can vary depending on their Member State and even within Member States. Disparities can exist in access to medicine, medical refunds or any psychological, financial or other aid a sufferer may need. Patients are far too often simply left to cope with their physical and mental distress. When questioned on the subject, the European Commission could only reply that this problem was a matter where powers lay entirely with the Member States. MEPs regarded this as unfair and insufficient as an answer and they have decided to contribute to the fight against multiple sclerosis by proposing a clear European strategy to combat it MEPs argue that the main goal of the health authorities in the EU should be to guarantee equal access to therapies and treatments as well as the provision of optimum services, through co-ordinated programmes drawn up in conjunction with the World Health Organisation. They also believe that patients' organisations, in particular the European Multiple Sclerosis Platform, should have a key role. Parliament 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 causes of multiple sclerosis, which remain to this day unknown. Moreover, Member States are urged to promote the development of specialised clinics and nursing homes designed to respond to the needs of younger persons with multiple sclerosis and similar diseases 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. It is pointed out that a specific characteristic of MS is that symptoms vary widely in intensity, which, as a result of criteria not adapted to MS, has resulted in patients being excluded from necessary support; urges Member States to take this into account in the provision of health care and social services to persons suffering from MS. Parliament 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. 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 similar diseases. On the issue of international cooperation, much closer cooperation 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 auto-immune diseases. The Commission, in cooperation with the Member States, is invited to devise and implement framework legislation which privileges job-retention for persons with multiple sclerosis and similar diseases, 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. Measures should be 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 such as MS; - be evaluated so as to feed into exchanges of ideas and experiences, particularly at EU level, which should help to develop and spread successful models for the benefit of all. Parliament requests that local and national authorities develop the built environment in such a way as to facilitate to a far greater degree access to buildings and transport for people with MS and similar illnesses, using uniform access standards. It underlines that access by people with MS and other disabilities cannot be achieved solely by removing environmental/physical barriers, but involves breaking down all obstacles which inhibit equal access to goods and services. Furthermore, Parliament adopted an amendment, which asks for the precautionary principle to apply to decisions in decisions affecting public health, notably in the use and disposal of toxic chemicals.?