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

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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 resultedin 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.