



Press release: 13th European Health Forum Gastein, 6 – 9 October 2010

Multiple sclerosis: Quality of care should not depend on place of residence – Experts call for benchmarks

More than 500,000 people in Europe are living with multiple sclerosis. Today, experts at the European Health Forum Gastein discussed the quality of care which varies greatly across the EU despite progress in modern treatment strategies. Policy steps suggested include creation of uniform standards and certification of specialty nursing.

Bad Hofgastein, October 6, 2010 – MS experts, European policy-makers, professional and patients' organisations at the European Health Forum Gastein (EHFG) today called for benchmark care provision across the EU and for governments and health services to provide improved access to specialized care for patients with multiple sclerosis.

About 600 decision makers in the fields of health policy, research, science and from patients' organizations from over 40 countries are currently convening at the European Union's most important health policy congress in Bad Hofgastein, Austria, to discuss crucial future topics related to Europe's health care systems.

500,000 MS patients in Europe – access to care varies widely

More than 500,000 people in Europe are currently diagnosed with MS, a complex, disabling condition and the most common neurological disease leading to permanent disability in young adults. It affects twice as many women as men and is usually first diagnosed between the ages of 20 and 40, which has a significant impact on patients' careers and families.

This progressive disease puts an enormous burden on the individuals and families affected by it and on European health care systems. Not all people with MS in Europe have sufficient access to adequate care from multidisciplinary teams. Despite the medical advances that have been made in the treatment of MS, including new treatments that will enhance the possibility to control the evolution of the disease, optimum treatment ultimately seems to depend on place of residence.

Speakers discussed that it is vital, particularly if they are faced with increasing disability, that people with MS can access co-ordinated care from a multi-disciplinary team, skilled and expert in MS. This includes a skilled nurse who can help address emotional and social matters, as well as medical aspects of the disease.

Significant disparities in MS care across Europe

According to the recently published MS-NEED European Survey, one in three nurses reported that standards of MS care are not adequately maintained in their country. The study, polling 280 MS nurses in six European countries, found considerable variations in the availability of specialized training and education for MS nurses across Europe. Overall, one in five nurses reported not receiving adequate training and education to support them in their day-to-day role.

Call for recognition of MS nursing as speciality

“We have learned with MS that great things happen when the public and private sectors come together. In the UK and certain other EU countries, specialized MS nurses are helping thousands of people with multiple sclerosis live more fulfilling, active lives. This and other success stories should be a benchmark across Europe and for all chronic diseases. To reduce economic burden while increasing quality of life is the ultimate goal,” Christoph Thalheim, Secretary General of the European MS Platform (EMSP), said in Gastein.

It is obvious from the discussions at the EHFG that the EMSP considers it crucial to recognize nursing in chronic conditions as a special qualification within the health care workforce in Europe and regards Multiple Sclerosis as a

frontrunner to find a way to unify, define and benchmark care provision to avoid geographical inequalities in patient care.

This recommendation was also vigorously backed by MS nurse representatives in Gastein. Amy Perrin Ross, President of the International Organization of Multiple Sclerosis Nurses (IOMSN): “We now have data to show how far MS nurses have come in expanding their role but also to point out further areas of development. A benchmark and standard for training and certification of MS nurses across Europe is needed to ensure equality of health service provisions and to improve the quality of life of MS patients and their families.”

Workshop 1: “Chronic care in Europe. Benchmarking Quality: Best practices in efficient care of Multiple Sclerosis - the growing role of nurses.” Organised by the European Multiple Sclerosis Platform and supported by an educational grant from Novartis Pharma AG: Wednesday, October 6, 2010

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