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EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

144/8 Rue Auguste Lambiotte
B-1030 Brussels | Belgium
T +32 2 304 5015
F +32 2 305 8011
E secretariat@emsp.org
www.emsp.org

EMSP Membership Newsletter: Bringing MS voices together

Table of Contents

Welcome message

Dear members of our European MS community,

What you have before you is the first edition of EMSP's Membership Newsletter, a collaborative publication made possible by the great support of MS societies across Europe.

The eight articles you will read are focused on access to MS treatment and connected topics.

Contributions range from informative overviews that demonstrate a good working relationship with relevant authorities to opinionated testimonies that require the strength of disclosure. They are all terrific examples of the power of MS advocacy.

This newsletter means to harness that power. We want to bring together the wise and diverse MS voices that represent people with MS all across the continent.

The objective for this publication is to become a marker of how well we can work together in pursuit of our common goal: higher quality of life for people living with MS and – hopefully in a not too distant future – a life without MS.

But how can our Membership Newsletter help you where you are?

Firstly, you can connect with the broader European MS community which we proudly represent.

Is access to care and employment high on your agenda? Here you are likely to find updates that cover at least one of your priorities.

Secondly, you can receive or share timely news on the main developments in the MS arena.

Do you need to get more and better MS information? Or are you ready to disseminate trusted MS sources? This is a safe and far-reaching channel.

Thirdly, you can positively affect the lives of people with MS living in other parts of Europe.

Did you manage to launch an MS registry or set up an MS rehabilitation centre? Why not tell MS societies in other countries how you did it? EMSP can help you share best practice across Europe.

This newsletter is part of our recently launched Membership Communications Network which all EMSP members are invited to join. The Network can truly reflect the power of MS voices coming together.

So read the newsletter, disseminate it and talk to us. We will always listen!

EMSP Secretariat

17 October 2016

Bulgaria http://www.emsp.org/member/ms-foundation-bulgaria/

Overview of MS treatment: statistics and challenges

By Daniela Shikova

The treatment of multiple sclerosis in Bulgaria has two main aspects - immunomodulatory therapy and symptomatic treatment.

The total number of people on treatment is currently 2,351. *At national level there are between 5,000 and 7,000 people living with MS.*

2,117 people have chosen the immunomodulatory therapy. This therapy is fully reimbursed by the National Health Insurance Fund (NHIF)[1].

The rest of the MS population relies on rehabilitation or partly on symptomatic treatment. This treatment type has a reimbursement percentage of between 50 and 100 percent.

Pictures:

EMSP's Under Pressure project

www.underpressureproject.org

Rehabilitation

MS patients have the right to two reimbursed visits at a rehabilitation center per year. Plus a reduced per visit cost for ten days every year - the so called 'light regime'.

But there are only a few MS rehabilitation centers in Bulgaria.

The upside is that there are no access obstacles for patients in getting prescription to attend such a center and receiving the guaranteed special fees and reimbursements.

The need for a national MS registry

Each year, MS is diagnosed mainly in young people between 30 and 34 years old, with a higher prevalence in women.

The existing records of people living with multiple sclerosis in Bulgaria do not correspond with each other and are mostly on paper. The indicators included are different for each hospital and have not been merged into a single database. Therefore, the official number of people with MS in the country cannot be accurately estimated.

In conclusion, there is a clear need to build a single electronic register of MS in Bulgaria.

[1] *Source: National Health Insurance Fund*

Denmark http://www.emsp.org/member/scleroseforeningen/

Let's talk about MS pain. Interview with an MS neurologist:

"We should be able to help the vast majority"

By Danish MS Society

The Danish MS Society published a new multiple sclerosis study in February 2016 showing that 14 percent of respondents suffer from severe pain every day or intermittently, while 32 percent suffer from moderate pain.

One of the respondents is 48-year-old Dorte Gravgaard from Jelling, a small town in Denmark. She says that pain is a big factor in her life:

"The pain is huge and affects everything in my life. I have days when the only thing I can do is sit in a chair. I never know what I will wake up to, and all my arrangements suffer from the risk of cancellation."

Pain as an MS symptom is by no means endemic to Denmark – and this prompted the Danish MS Society to share an interview with a specialist on the topic, in the hope that it will benefit people living with MS across all of Europe.

The interviewee is Henrik Boye Jensen, a neurologist at the MS Clinic at Odense University Hospital.

The hot stove

The so-called neuropathic pain is caused by the nerve damage specific to MS.

"Pain is like a danger sign telling you that you should move your hand from the hot stove. But nerve damage means that more pain signals are allowed to pass through. Or that pain signals are damaged.

In the case of MS pain, there is no hot stove. But the pain patients feel is real enough", explains Henrik Boye Jensen.

Pain as a bumpy road

"Imagine the sense of pain as a bumpy road for which you need a big Jeep to drive through. Touch, on the other hand, is like a neat highway.

Nerve damage in some people with MS means that certain stimuli that should be registered by the sense of touch are being registered by the feeling of pain instead.

All the small cars who were supposed to drive on the highway have come to race on the bumpy dirt road ", continues Henrik Boye Jensen.

Managing expectations

"Let's stay in this picture with roads and cars. I cannot remove the road that the cars drive on. But I can close the sideways to the road for some of the cars", says Henrik Boye Jensen introducing a topic he feels strongly about.

Namely, that medications can only rarely get all the neuropathic pain to disappear.

The neurologist explains that he tries to adjust the expectations of his patients accordingly:

"I consider it a success if we can get rid of half the MS pain of my patients. But if I do not get them to understand that half the pain is the goal, then they will be disappointed if all the pain does not disappear. That is why I always try to align their expectations to mine."

Pain is a work of patience

There are different kinds of medicines to help MS patients with pain. But the pain treatment is often a work of patience for both patient and doctor.

"I usually try with one of the older antidepressants first because it is well tolerated by many and works well for up to 30 percent of patients. If it does not work, I have many other options", adds Henrik Boye Jensen.

Efficacy and side-effects

Prescriptions for pain require collaboration between neurologists, nurses and the patient. And there is also a risk of side effects. There is - Henrik Boye Jensen concludes - no doubt that the vast majority of patients with neuropathic pain should be able to get medical help:

"It is always an individual assessment, what the patient can and will live with when it comes to side-effects. We cannot help all patients. But we should be able to help the majority."

According to MS International Federation's (MSIF) Atlas of MS database, around 13,000 people currently live with MS in Denmark.

Ireland http://www.emsp.org/member/ms-society-of-ireland/

The 'rocky road' to prescription and reimbursement

By Harriet Doig

The MS Society of Ireland writes about the often complicated process behind prescription and reimbursement of new MS treatments for people living with MS in the country.

Fampridine

The drug was made available by the Health Service Executive (HSE) in October 2015 - for people with MS who satisfy the so-called 'responder protocol'. This refers to a set of criteria and tests meant to determine if a patient responded to fampridine.

The current process includes tests of mobility and kidney function followed by a prescription for the duration of two to four weeks. After this, the tests will be re-administered. Those demonstrating a 20 percent or greater improvement in mobility will have fampridine paid for by the HSE.

Initially, there were various difficulties with the system owing to the fact that it was the first time that the 'responder basis' was introduced at national level.

MS Ireland met with senior staff from the HSE to discuss these difficulties and the organisation has produced a set of 'Frequently Asked Questions' to guide people with MS through the process.

Alemtuzumab and Natalizumab

When the HSE approves reimbursement of products that are administered in hospitals, such as the two drugs mentioned above, it is the responsibility of the hospitals to provide them upon prescription.

There is currently no national funding system for these medications - which have come into the market over the past decade.

MS Ireland is aware of many instances where hospitals have refused or restricted access to treatment in order to contain costs. This means that access to treatment depends on where MS patients live and what hospital they attend.

Access to Medicines Handbook

Over the past years, MS Ireland has advocated for the establishment of a national, guaranteed funding system for these medications. The negotiations on the topic are ongoing.

With the goal of improving understanding of and access to MS treatments, in August 2015 MS Ireland launched a handbook - Access to Medicines Campaign Handbook.

MS Ireland's report 'Societal Costs of Multiple Sclerosis in Ireland 2015' estimated this number to be 9,000.

Poland http://www.emsp.org/member/polskie-towarzystowo-stwardnienia-rozsianego/

Overcoming the challenges of reimbursement

By Marta Szantroch

Access to MS treatment in Poland has never been straightforward, and drugs reimbursed through the national healthcare system have always been difficult to obtain.

Currently there are two reimbursement programmes, for 1st and 2nd line treatment.

1st line treatment targets relapsing-remitting MS. It is not age or time limited, so it assures accessibility as long as it is effective for the patient. The program includes: interferon beta, glatiramer acetate, peginterferon beta and fumarate dimethyl.

Time and age limitations

2nd line treatment targets quickly progressing relapsing-remitting MS and is usually administered when 1st line medicines are not having the desired effect. In this case, people with MS can be treated with fingolimod and natalizumab.

Unfortunately, these treatments are restricted to a period of five years for each patient even when they show positive results. They are also age-dependent: patients under 18 years old do not have access.

The new generation drugs such as alemtuzumab and teriflunomid have entered the Polish market but are not covered by the healthcare system.

Efficient MS advocacy

In Poland, MS reimbursement programmes have been changing constantly over the years. But thanks to MS advocacy groups and dedicated decision-makers, the change is starting to be for the better.

For example, a couple of years ago, before intensive public pressure from MS campaigners, 1st line treatment was also restricted to five years. In 2015, the age restriction for 1st line treatment was also lifted enabling children of all ages to use interferons and glatimer acetate.

Finally, from July 2016 two additional drugs - peginterferon beta and dimethyl fumarate – have become available as a part of 1st line treatment. This decision was greeted with open arms by the Polish MS Society (PTSR) and its constituency and there were plenty of positive reactions.

The barriers ahead

But PTSR's Secretary General, Magdalena Fac-Skhirtladze, says the road towards a satisfactory MS reimbursement system is long:

"There are still limitations in access to MS treatment at national level. People with MS face many barriers. Insufficient financial resources mean that many of our patients have to wait to obtain the drugs they need.

Then there are some regions in Poland where the waiting time for reimbursed treatment reaches two years. We need to address this issue, as time matters in MS.

We are also not sure how the admission of new drugs will look in practice and how much money the hospitals will receive for the reimbursement process."

Poland has one of the biggest MS populations in Europe, with estimates of between 45,000 and 55,000 people.

Spain http://www.emsp.org/member/asociacion-espanola-de-esclerosis-multiple-aedem-cocemfe/

MS testimony: How I learned to live with disease progression

By Jacobo Santamarta Barral

I am 31 years old at the moment and I was diagnosed with MS in 2007. At the beginning I had no idea what "multiple sclerosis" meant and wasn't aware of its consequences.

In fact, I believe that this is the hardest thing: living with the uncertainty of not knowing what is happening to you and how you are going to handle it.

I had my first symptoms in 2004 when I was working as a waiter while I studying Law. I had two relapses and the symptoms were double vision and pins and needles on the lower part of my legs. Back then, I didn't even think about going to see a doctor. I thought it was just exhaustion or stress.

When I finally went to the doctor and received my diagnosis, I received the recommendation to start treatment right away. The doctor gave me the four suitable options and also provided the information I needed to make a choice.

Time for change?

After learning about MS I was sure it was not going to change my life. So I continued with my studies even though the treatment made me more tired and it got harder to even attend class, let alone also work.

Upon further analyses, my doctor saw the treatment was affecting my liver so she decided to change it to glatiramer acetate - which I took for a few years and it even allowed me to spend a student exchange year in the US.

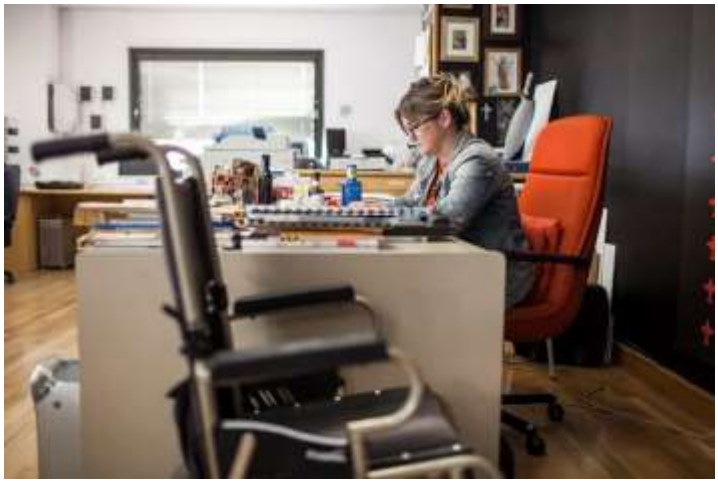
When I went back to Spain I decided to move to Madrid to follow a Master in Law for one year since I was not experiencing any major symptoms at the time. I also managed to work and earn some extra money.

Another treatment

But in the last two months of that year I started feeling a lot of fatigue and I was having trouble with my vision. I delayed the visit to my doctor. But my symptoms got so sudden that I felt I had to explain to those around me what was happening. And with this I finally went to see my doctor again.

My doctor decided to change my treatment to natalizumab. This is the drug I am still taking as it fits my medical history and has an easier administration method.

After finishing my studies I went back to my home town and spent two weeks in the hospital. When I came out I was still coping with the symptoms but I wanted to keep living a normal life.



Working and managing MS

I applied for a job, taking advantage of my disability certificate, which made it much easier. In Spain, companies get some tax advantages for hiring people with a disability. I was then successfully employed in the Human Resources Department.

I told them I had MS in my first day at work. I was moved to Accounting soon after.

After those first six months I realised the company did not want me to be involved in the work as much as I was supposed to or willing to be. Even if I gave my best, it was not going to change my position and the work I was going to do.

So I started doing what I really wanted: concentrating on Intellectual Property Law. I qualified to be an IP lawyer in Spain. And the same time I studied foreign languages.

Accepting the challenges of MS

During these last five years my condition has got a little worse because I cannot walk long distances and I shake quite a lot. At present I combine sick leave with Law studies and I also collaborate with the MS association in my city as much as I can.

I have to say I am lucky that I had the opportunity to make the changes I needed. The progression of the illness has not stopped but I am sure that has nothing to do with my choice of medication, but because of the illness itself.

According to the MS International Federation's (MSIF) Atlas of MS, around 46,000 people currently live with MS in Spain.

Switzerland http://www.emsp.org/member/schweizerische-multiple-sklerose-gesellschaft-9smsg0/

MS registry: answering key healthcare questions

By Marc Lutz

The standard of healthcare in Switzerland is generally very high and access to related services is guaranteed and covered by a statutory health-insurance system.

A federalist structure puts healthcare provision and funding in the hands of 26 Cantons, thus limiting the state's influence.

But transparency is limited and there is an overall lack of comprehensive statistical data.

It remains unclear, for instance, how many people with MS live in Switzerland. A rough estimate of 10,000 is most probably too low.

The recent launch of the Swiss Multiple Sclerosis Registry is a big step towards tackling such problems and finding answers to previously unanswered questions regarding access to healthcare.

The Swiss Multiple Sclerosis Registry[1]

Multiple sclerosis disease management requires active involvement of people with MS, their families and caregivers. It also relies on a collaboration between healthcare professionals.

However, in Switzerland there is a widely recognised lack of information and high-quality evidence on key topics such as: disease epidemiology, long-term efficacy and safety of disease-modifying drugs, access to and uptake of MS treatments and care, and patients' needs and preferences.

Based on an initiative of the Swiss MS Society, the Swiss Multiple Sclerosis Registry (SMSR) was launched on 25 June 2016. It represents a collaborative effort by numerous MS caregivers, researchers and persons with MS. It is hosted by the Epidemiology, Biostatistics and Prevention Institute at the University of Zurich.

This patient-centered, nationwide, longitudinal study is open to all adult people with MS living in Switzerland. The registry will involve people with MS not only as study subjects but also as experts whose opinions and experiences are valued.

Citizen science

The Swiss MS Registry therefore takes a 'citizen science' approach. Its main objectives:

- to estimate the prevalence of MS in Switzerland and to monitor epidemiologic trends over time;
- to estimate the burden of MS on patients, families or proxies;
- to establish a flexible infrastructure and a network that enables and facilitates interdisciplinary research.

The SMSR will be a unique addition to the Swiss and European MS research landscape for its innovative design and strong involvement of people with MS and their relatives in data collection and research.

[1]*Summary of: V. von Wyl, N. Steinemann, V. Ajdacic, J. Kuhle, C. Vaney, M. Puhan, C. Lotter, J. Kesselring. THE SWISS MULTIPLE SCLEROSIS REGISTRY (SMSR): A CITIZEN SCIENCE PLATFORM FOR MS RESEARCH. 2016.*

United Kingdom

http://www.emsp.org/member/the-multiple-sclerosis-society-of-great-britain-and-northern-ireland/

MS treatment: is access still a lottery?

By Georgina Carr

Building on the unprecedented *My MS My Needs* research from 2012-2013, the UK MS Society carried out a second such survey earlier this year. More than 11,000 people with MS responded.

The study found that access to disease-modifying treatments (DMTs) in the UK - among those who could benefit - has increased significantly since 2013, from 40 to 56 percent.

Challenges

The worrying news, however, is that just 12 percent of respondents have been offered a care plan or care plan review, and 16 percent believe their health and care professionals do not work well together at all.

Variation in access to services very much still exists.

Concerns

We are concerned that a sizeable minority of people with MS are at risk of being forgotten by the National Health Service (NHS).

Indeed, one in ten of those who could potentially benefit from a DMT haven not seen an MS nurse or neurologist for over a year. Among this group, just 12 percent are taking a DMT.

In contrast, among those who saw both an MS nurse and a neurologist, 73 percent are taking a DMT.

The UK MS Society believes that every person with MS should be able to access the right treatment at the right time, no matter where they live.

Further information is available in the study report: https://www.mssociety.org.uk/accesslottery.

According to the Atlas of MS database build by the MS International Federation (MSIF), there are around 100,000 people living with MS in the UK.

Guest contributor: Romania http://www.centrulsmile.ro/

MS testimony: "Access to treatment should not be a matter of luck"

By Stanca Potra

I consider myself a lucky person. I am lucky to have caught my MS early enough to still be considered CIS (Clinically Isolated Syndrome). It happened after a small optic neuritis.

I received treatment within two months from my diagnosis and had no MRI modification in four years, which means the treatment I am on (Interferon beta-1a) must be working for me.

If you were living in Romania, you would understand just how much this means.

We may be a country in the European Union, but our standards for treating MS patients are way below EU standards.

There are as many as 10,000 people diagnosed with MS in Romania, but only 3,000 receive treatment, and thousands others have been living with this condition for years but have not yet received the right diagnosis.

Until last year, only a limited number of people could get access to treatment, through what is called 'The National Program'.

No luxury for MS patients in Romania

At present, The National Program is open for all Romanian MS patients, which is truly a step forward. But many people with MS still cannot access the Program, either because of their own ignorance or misconceived ideas in regards to the treatment, or simply because they are rejected.

Since the Program opened, the number increased with several hundreds of people, while thousands are still waiting to be included or to be properly diagnosed.

As I mentioned, I was lucky enough to be included in the Program soon after my diagnosis and to be given a treatment that works for me and that is available in our country.

But being an MS patient in Romania does not give you the luxury of switching treatments or asking for a specific one you consider more appropriate for your condition (though treatment

can be changed after a while if found inadequate).

The moment you enter the Program, based on the severity of your condition, you are attributed either an interferon, glatimer acetate or natalizumab perfusion as a 2nd line of treatment, if the so-called 1st line failed.

The prescription is strictly up to the Commission that included you in the Program - leaving the patients, as well as their neurologists with no influence whatsoever.

You do not get to make an informed decision about how you want to approach your condition, you cannot object to the appointed treatment, and even if you could, you do not have many choices available.

What the future holds

In 2017, the National Program will include the first oral treatment for MS, teriflunomide, marking yet another small step forward.

The progress is insignificant though in comparison to the medical advances in the field.

While most European countries benefit from newly developed treatments like dimethyl fumarate, fingolimod and alemtuzumab, the prospect of having them as part of our National Program is somewhere very far in the future.

And by the time the Government understands that the cost for treatment is always less than the cost for social care support, many more people with MS will find themselves in the position of asking for that financial support instead of contributing to the country's productivity.

If there is something that can be done to influence the progression of our MS, to keep us healthier and active for longer, we should all stand together and demand equal treatment for all European citizens.

But yes, I am lucky enough to have a treatment that works for me and do not need any of these latest drugs yet. The problem is that access to treatment should not be a question of luck. Being able to carry on with your active life should not be a gamble at the mercy of any country's medical system.