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EUROPEAN
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PLATFORM

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EMSP Membership Newsletter: Bringing MS voices together

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Bulgaria <http://www.emsp.org/bulgaria/>

2017 goals: MS registry and national representation

By Daniela Shikova

The Bulgarian MS Society announced it has obtained the status of administrator of personal data under national law. This paves the way for the realisation of two long-awaited projects: setting up a registry of patients with multiple sclerosis and achieving the formal status of nationally representative organisation.

The registry

As mentioned in the first edition of EMSP's Membership Newsletter, Bulgaria is currently lacking a national MS registry. This initiative would address a number of challenges, starting with an accurate overview of the total number of people living with multiple sclerosis in the country. *The estimation is between 5,000 and 7,000 persons.* Moreover, a registry would merge the MS records and indicators currently spread across various hospitals into a single database. It would also collect data on patients with Myasthenia gravis (MG), an autoimmune condition causing muscle weakness.



Picture: Under Pressure Project (www.underpressureproject.eu)

National representation

Becoming a nationally representative organisation by law will also bring important opportunities. For example, the Bulgarian MS Society will be able to implement reforms in social and healthcare policy related to the access to treatment and social integration of MS patients.

In order to obtain this status, the MS Society will have to demonstrate coverage of 30 percent of the municipalities in Bulgaria and to present to the Ministry of Health a list of 1,800 people - including both persons living with disability and their partners, relatives or friends.

Therefore, the MS society has submitted an open call for all patients and their supporters asking them to send their personal details, including proof of disability assessment. This information will also help with the creation of the MS and MG registry.

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Ireland <http://www.emsp.org/ireland/>

Availability issues for approved drugs. Case study: Nabiximols

By Harriet Doig

MS Ireland counts the availability and reimbursement of MS drugs among its priorities as a patient organisation. Case studies on reimbursement of drugs such as Alemtuzumab, Natalizumab and Fampridine were presented in the first edition of EMSP's Membership Newsletter. For this edition MS Ireland focuses on the availability of Nabiximols (with the trade name of Sativex), a prescription medicine that treats spasticity symptoms associated with MS for people who have not responded to other medicines.

Licensed but unavailable

As it contains cannabinoid THC, Nabiximols required a process of legislative change before it could be licensed and prescribed. This process was completed in July 2014. However, in October that year the National Centre for Pharmacoeconomics (NCPE) - which conducts health technology assessments of potential new medicines - issued a summary report recommending that the Health Service Executive (HSE) did not reimburse Nabiximols at the submitted price.

Further negotiations between all relevant parties followed but were unsuccessful: the drug remains unavailable to people with MS in Ireland at present. Nabiximols is also not available to purchase privately due to supply chain logistics involving transportation and storage.

Patient advocacy

MS Ireland has been engaging in advocacy work to try and make Nabiximols available to people with MS at national level. The patient organisation has twice written to the Minister for Health in 2016, outlining why this drug should be made available. It has also highlighted the issue in the media: spokespeople with MS have shared their stories on how not being able to get Nabiximols impacts them. Furthermore, MS Ireland has been in contact with the pharmaceutical company that markets Nabiximols to try and encourage them to reengage with the HSE. The organisation is currently gathering further testimonials from people with MS and plans to make a detailed submission to the HSE in 2017.

MS Ireland is inviting other EMSP members to share their experiences - if any - of advocating towards the availability of Nabiximols in their countries. Those interested in the topic can contact Harriet Doig at harrieted@ms-society.ie.

The report 'Societal Costs of Multiple Sclerosis in Ireland 2015' estimated the number of people with MS living in the country to be around 9,000.

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Poland <http://www.emsp.org/poland/>

Rehabilitation through sport. MS testimony

By Milena Trojanowska

In 2015 I ran a marathon. It was almost 8 years after I had my first MS symptoms. I am Milena and this is my story.

The 2015 experience helped me realise that I want to support other people with MS in Poland. So last year I organised an MS bike tour. It was the first event of its kind at national level. We were 20 participants and together we biked over 300 kilometers in seven days, from Augustów to Hajnówka, extremely picturesque parts of Poland. There was a fair amount of effort but also lots of laughter.



Picture: Milena Trojanowska (personal archive)

The everyday programme

But let's start with the beginning. Many years ago, when thinking about rehabilitation in MS, I was picturing myself inside a hall full of sports equipment, with a clock running down the time allocated for my exercises under the coordination of a physiotherapist dressed in white sportswear. But the MS experience taught me that rehabilitation is more than that. It is not just one visit at a specialised clinic and two weeks of gym during a calendar year – the rehabilitation programme reimbursed by the Polish National Fund. The body of a person with a chronic disease requires plenty of effort and everyday exercises to stay in the best possible condition.

'Proper' running

I also used to think that running was not a sport for people living with an incurable disease. But one day I dusted off my running shoes and went to stretch my legs. I had the help of a dedicated professional physiotherapist and the will start a proper MS rehabilitation programme. I was running several times a week, covering different distances. Then I learned about a running group in my city and I met with them. They turned out to be fantastic people who cheered me on and helped me keep faith in my ultimate goal: completing a marathon (42 km).

While on my marathon quest I started to leave the house more often, eat healthy and regularly, and always get my medical check-ups. My passion for running was also helping me socialise more. I was making friends and meeting new people all the time. We were sharing personal track records and planning our next races together.



Picture: The 'Jazda z SM' cycling tour (Milena Trojanowska's archive)

The pleasure of rehabilitation

As my passion for sports and rehabilitation grew stronger, I felt the need to share it with others. I started a blog and looked for sponsors who would help me run and also raise money for MS. This was a good way to start my MS advocacy career. After a while, I came up with the idea of extending my activities to biking. And that's how the 7-day biking tour came about. It also had a fitting name: 'Jazda z SM' (which translates both as 'Drive with MS' and as 'MS, go away!'). With the help of the Polish MS Society, I am planning to organise more bike tours. Together, we still have much to prove: above all, that rehabilitation in MS can be a great pleasure.

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

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Portugal <http://www.emsp.org/portugal/>

Providing modern MS rehabilitation

By SPEM

The Portuguese MS Society (SPEM) plans to relocate, expand and modernise the only rehabilitation centre in the country exclusively dedicated to people living with multiple sclerosis. The related work is to be completed by the end of 2017.

The MS Neuro Rehabilitation Centre in Lisbon operates since 2004, offering specialised care. SPEM intends to renovate a nearby building and transfer the entire centre. The process includes improving the working conditions and technical facilities. In this way, it will also be possible to accommodate more staff.

A dream come true

SPEM's Vice-President, Susana Protásio, speaks about this project as a 'dream come true':

"The centre's current space and facilities were evidently not coping with the increasing number of people looking for our physiotherapy, as well as our occupational and speech therapy services.

This is an important goal for us in 2017. We will be able to help a larger group of people with MS and other neurological disorders.”

As Ms Protásio indicates, the new centre will be able to welcome 200 patients every month, doubling the current number. Furthermore, it will become available to people with other neurological diseases, such as Alzheimer’s, Parkinson’s or ALS (Amyotrophic Lateral Sclerosis).



Picture: Carolina Rodrigues, physiotherapist, assisting an MS patient (SPEM archive)

40,000 euros for ‘vital’ services

The total costs are expected to be in the region of 40,000 euros. But the benefits for those affected are priceless. Rosário Barreiro has been visiting the Lisbon centre for 12 years and says it provides much more than MS therapies:

“The centre is vital in regaining some of my body functions because the medication by itself is not enough. The physiotherapy service helps me on a daily basis. I also like to come here because the staff listen to my problems, talk to me and become my confidants.

The time spent here makes a huge difference for me. The bicycle is helping me a lot. Before, I couldn’t even pedal. I’m much better now. I’m regaining my muscle mass, improving my fatigue levels and my resistance.”



Picture: Fátima Ruivo, speech therapist, during one of her sessions

(SPEM archive)

‘It makes me happy’

Ana Laia has only been going to the centre for four months but says the exercises and the company have already made her a happier person:

“It helps with my mobility and allows me to be more comfortable with my body. It is also a good reason to get out of the house. In the past, I used to spend all my days on the couch. But now I’ve noticed an increase in my stamina and balance. Plus, nobody pities me here.”

The Portuguese MS Society was able to secure most of the money needed for the new rehabilitation centre through fundraising. And is currently negotiating at national and European level for additional funds.

According to the [Atlas of MS](#), 6,500 people live with multiple sclerosis in Portugal.

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Republic of Moldova <http://www.emsp.org/moldova/>

No crutches, no benefits: The disability assessment battle

By Alina Verbnî

There are many battles facing people living with multiple sclerosis. In the Republic of Moldova, one of the toughest MS battlegrounds is fuelled by a poor piece of legislation: the one regarding disability assessment. Law 60 from 30 March 2012 restricts access to disability benefits as it does not mention multiple sclerosis among health conditions that enable the State to assess the level of disability, the necessary pre-condition.

A consequence of this Law is that people with relapsing-remitting MS (RRMS) cannot be assessed as disabled unless they have physical signs of disability, more typical for progressive MS. The most common symptoms of RRMS are described by specialists as “invisible”. They include fatigue, cognitive issues and pain.

Will the “real” people with MS please stand up?

The problems do not stop here. Those people with MS that pass the disability assessment test encounter yet another hurdle. The Law requires a year-by-year extension of the personal disability dossier. Not acknowledging MS, it does not take into consideration that - to date - it is an incurable condition. In practice, this can mean huge waiting queues at the hospital. Very often, people with mobility problems have to stand four hours before they can talk to a doctor.

“We need a more flexible Law, one that would enable people with MS to pass the disability assessment regardless of whether they are in an early or advanced stage of their condition. At the moment, it’s a case of no crutches, no benefits”, says the President of the Multiple Sclerosis Society of Moldova (MMSM), Alina Verbnîi.

Call for information

Ms Verbnîi adds that people with MS in the country could also benefit from public information campaigns on access to disability benefits:

“Some of those newly diagnosed are not even aware that they can they can have a disability assessment and claim related benefits, let alone being familiar with the concrete steps to follow in this process. An additional solution for this problem would be an MS Information Centre.”

In the Republic of Moldova, disability benefits include an allowance calculated according to the number of years in employment and a reduction for public transport.

MMSM estimates that more than 1,000 people live with multiple sclerosis at national level.

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Russia <http://www.emsp.org/russia/>

MS rehabilitation, a family programme

By Pavel Zlobin

This is a report about the construction and activity of an MS rehabilitation centre. It is also a story about the efforts invested by the local and national patient organisations in Russia to build this centre for people with multiple sclerosis and other neurological disorders.

Medical and non-medical rehabilitation are both very important for people living with MS and other chronic disorders. Both rehabilitation methods help those affected control their health and manage their social inclusion. In these cases, rehabilitation should become routine practice.

Don’t forget the families

Rehabilitation also needs to be comprehensive: for those directly affected by disability but also for those indirectly affected. For their families, more often than not. Ten years ago, two MS advocates in the city of Samara came to this conclusion. MS advocate Svetlana Goronkova - who would go on to become 2013 International Person with MS and Oleg Ipatov – a dedicated representative of the Russian Multiple Sclerosis Society. They started making plans to build a rehabilitation centre. They attracted four other organisations for disabled people.

Uniting their voices, they lobbied political decision-makers. One of their most convincing arguments was that such a centre would relieve the burden on health authorities. They also remembered to put their initial idea on the table: family support.



Picture: Activities at the Russian MS rehabilitation centre (Russian MS Society)

The rehabilitation coalition

In time, the plan grew more specific: the centre required room to accommodate social workers, physical activities and two computer classes. The rehabilitation coalition persevered and within five years they succeeded. They found a 360 square meters building and premises, and attracted funding and equipment. Total value: 135,000 euros.

The Rehabilitation Centre finally opened in 2013. Today it is carrying out various activities of medical, social, educational, psychological and physical nature. Trainings conducted here cover self-help and self-control, communications skills, social behaviour as well as household adaptation techniques. The centre is also making an effort to address individual issues, such as the improvement of living conditions.



Picture: Activities at the Russian MS rehabilitation centre (Russian MS Society)

A few 2015 statistics: the centre conducted 12 'schools for patients', 15 psychological trainings, more than 120 music-therapy sessions and classes in applied arts, and about 25 thematic events. It hosted aspects of everyday life. The patients and their families enjoyed them. And they still do.

The number of people with multiple sclerosis living in Russia is estimated at 150,000.

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Spain <http://www.emsp.org/member/esclerosis-multiple-espana/>

MS physical activity platform launched online

By Sandra Fernández

The patient organisation Multiple Sclerosis Spain (EME) moved its popular Platform for Promotion of Physical Activity in MS online in a bid to reach a broader audience of involved healthcare professionals (HCPs). The unveiling of the online version took place on 18 December 2016, marking the National Multiple Sclerosis Day.

Outreach to multidisciplinary team

The Platform was set up in June 2015 to encourage HCPs to promote physical activity among people with MS according to their possibilities and the stage of their condition. This initiative targets HCPs working in rehabilitation centres, in particular. One of the main priorities is to provide basic training to so-called multidisciplinary teams (physiotherapists, nurses, social workers etc.) enabling them to improve the quality of life of people with MS. The project is run in collaboration with corporate partner Sanofi Genzyme.



Picture: EME Archive

In line with expectations

EME's initiative synchronises with health policies which are increasingly focused on prevention systems. It also upholds recent scientific evidence confirming the positive effects of physical activity. Moreover, the Platform matches the expectations of people with MS who are becoming experts in self-management of their health and feel the need to promote physical activity. The Platform's launch reflected its holistic approach: it took place during a meeting between HCPs specialised in MS where people with MS were also invited. Two renowned figures present there were Dr. Rafael Arroyo - Head of the Department of Neurology of the University Hospital Quirónsalud Madrid; and MS athlete Ramon Arroyo - a well-known MS advocate.

How it works

The Platform collects and shares specialised contents in the areas of physical therapy, psychology, nutrition and healthy habits. It facilitates a multitude of resources, guides and experiences of different professionals from MS-related national and international organisations. Those interested can access it at <http://actividadfisica.esclerosismultiple.com> (content in Spanish).

According to the [Atlas of MS](#), 46,000 people currently live with MS in Spain.

Kosovo

MS diagnosis testimony: I feared it was cancer

By Labinot Demi

My name is Labinot Demi, I live in Kosovo and I was diagnosed with multiple sclerosis in 2015. But I had been experiencing related symptoms since 2013. This is my personal story.

At first, I put the MS symptoms down to stress. I was President of the football club FC Kosova Vushtrri who won Kosovo Super League in 2014, a premiere for the city. In parallel, I was managing a marketing agency with more than 40 employees. I resigned from the club and got rid of the stress factor but soon afterwards I started fearing I had cancer. I was experiencing groin pains and I was sure something was wrong with me.

'The worst night of my life'

In August 2014 I became a father but on that very evening I couldn't feel joy. I urinated blood. Instead of becoming the best night of my life, it was the worst night of my life.

I visited more than ten urologists in my region and outside the country but received no clear verdict. I became depressed and anxious. I couldn't be on my own and I was lucky to have the great support of my wife. I went on therapy but I was still feeling fatigued.



Picture: Labinot Demi (personal archive)

God and Dr Google

In September 2015 I started having long headaches. I first experienced them in the Milan subway so I assumed that they were normal for underground travel. Only they didn't stop. When I returned to Pristina I finally went to see a neurologist who recommended an MRI test. The radiologist told me of some lesions but I did not receive the diagnosis until the next day. The night before I did not sleep: I went on the internet and learned of more than 1,000 types of cancer associated with

neurological disorders. The next day I had to go through two more hours of waiting in the neurological department before the doctor finally told me it was multiple sclerosis.

So I went from praying to God I didn't have cancer to becoming best friends with Dr. Google who taught me a lot about MS. I then visited several medical centres in Macedonia, Serbia, Kosovo, Italy and other countries.

The Association

I consulted other neurologists and ran the MRI test four more times. The doctors told me I didn't have to start therapy immediately since I only had a small active lesion. The symptoms also became less frequent.

Wanting to raise awareness of this disease, in 2016 I started a national Association of Multiple Sclerosis. My aim was to bring together people who have the same problem. I began by helping others with information and some medication. I also listened to those who were diagnosed before me. We met four times in the first six months, including to mark World MS Day. The Association has grown to 20 members, at present. Our ambition for the near future is to join international MS networks and platforms.

As for me, I continue to work and I have changed my lifestyle. I play football three times a week, I control my diet and every day I learn something new about MS.

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