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EMSP Membership Newsletter: Bringing MS voices together

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Estonia: www.emsp.org/estonia

Wireless monitoring system: a solution to support MS examinations

By Katrin Rüütel

The Estonian MS Society is involved in the development of a wireless device aiming to help with the remote examination of people living with multiple sclerosis in the country. The Society reports 'positive' results after having measured key aspects such as balance and mobility, in some cases even during relapses and recovery.

According to the Society, this monitoring device (MEMS) is able to collect and transmit reliable data about people with MS on treatment. The system could significantly reduce the need for visits to medical centres without compromising on quality of care.

Find a video presentation [here](#).



MS advocate Pille-Katrin Siilmann Levin tests the wireless MS monitoring device

Adding value

The wireless device was tested on 44 people with MS - either at home or in the office - and showed potential to add value to neurological examinations.

Different tests demonstrated that the best location for the MEMS transmitter was the chest area - or sternal region - as applying it on the head or extremities implies picking up too much noise.

The most reliable data were received from standard standing positions. However, in some people with MS the readings were influenced by significant fatigue. This led to the conclusion that the measurements should be performed during the time of day when the respective person is less fatigued.

One important mention: the transmitter was not able to identify all relapses as they can occur with isolated sensory or visual signs.



A closer look at the MEMS transmitter

‘Feasible system’

Long term follow-up of people with MS testing the MEMS transmitter at home demonstrated the feasibility of this system provided the persons involved had a motivation to perform the measurements, the Estonian MS Society concludes.

Between 1,300 and 1,400 are estimated to live with MS in Estonia. The Estonian MS Society gathers 400 patients and carers through its seven regional branches. A third of them are actively involved in the organisation.

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Germany: www.emsp.org/germany

Reaching out to the MS public

By DMSG

The German MS Society (DMSG) is focusing on advocacy and awareness-raising in its 2017 outreach strategy to national MS communities.

DMSG shares three of its exciting new initiatives with a view to inspiring other MS societies across Europe.

World MS Day competition

In an initiative meant to broaden the supporter base, eliminate barriers and tackle prejudice, DMSG has called on its constituency (see below picture) to submit proposals for a poster and motto to be used in this year’s nationwide campaign dedicated to World MS Day (31 May).

The proposals impressed the designated jury with their creativity. This experience also provided DMSG with a valuable insight into the MS-related knowledge, hopes and fears of people living with this condition in Germany.

The winners will be announced by the end of April and will have the opportunity to see their creations promoted across the country. Find more information [here](#) (in German).



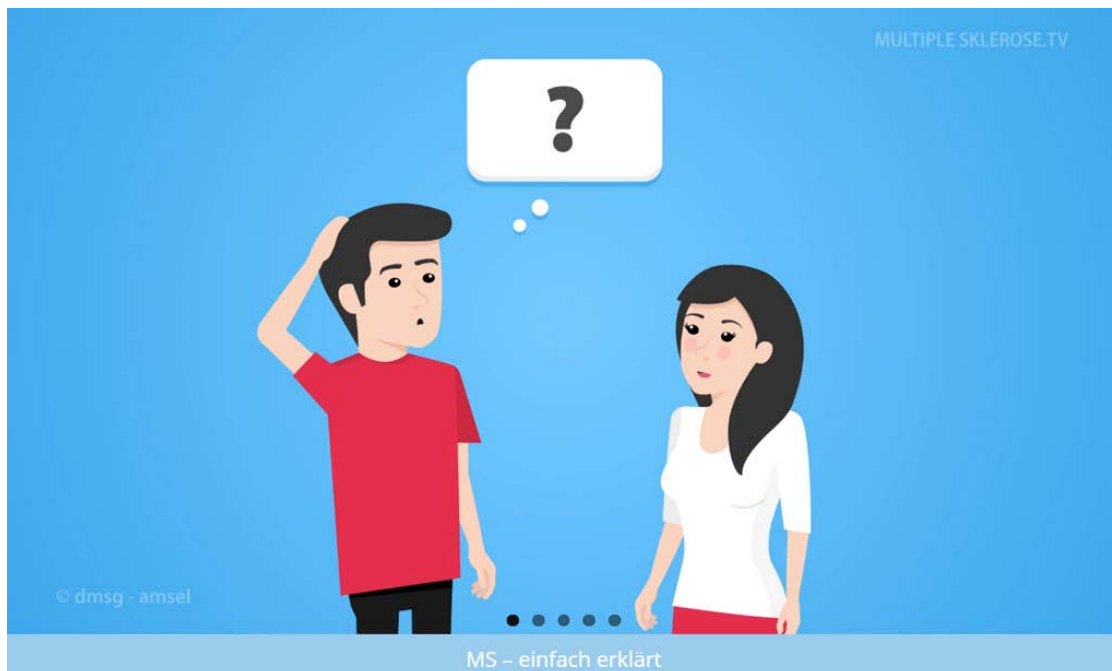
Answering MS questions

MS is known as the disease of 1,000 faces. Its symptoms are so complex that they impact all aspects of everyday life and raise many questions from those affected.

This is why DMSG has created a multimedia digital platform that hosts short explanatory video animations on various MS challenges and treatment solutions. The central characters of these videos are Anna, Niels, Julia and Tom. Together they answer many questions about MS: How does it affect people? How to react to the diagnosis? Is life in a wheelchair unavoidable?

The multimedia initiative (pictured below) will continue throughout 2017 with more videos on important topics such as working with MS, the relation between MS and the PML viral disease and driving with MS.

Find more information [here](#).



MS parenthood

One third of the 200,000 people living with MS in Germany have between 20 and 40 years of age. For many of them topics like pregnancy and parenthood are as sensitive as they are important given the unpredictability of their condition.

In order to come to their aid DMSG and 16 regional branches have launched a national helpline. Through this telephone service those interested can receive professional counseling. One of the healthcare professionals who will be answering questions is Dr. Kerstin Hellwig, senior physician at the Saint Josef-Hospital, Bochum, and member of the Medical Advisory Board of DMSG.

Find more information [here](#).

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Russia: www.emsp.org/russia

Introducing the underwater ‘barracuda’ wheelchair

By Pavel Zlobin

The Russian MS Society explores novel ways of expanding the mobility for people living with multiple sclerosis. In this edition of EMSP’s Membership Newsletter they are promoting an intrepid initiative: the underwater wheelchair.

‘Why not?’ say representatives of the Society. Especially since - they point out quoting [an article](#) from the Regnum press agency – this wheelchair has already been tested.

According to the article, Russian inventor Igor Skikevich has produced a special design that can navigate under water (as pictured below).



The MS diver

The hand-maneuvered four-wheel vehicle becomes amphibian under Mr Skikevich's design: with 'fins' on both sides and special propellers which can be activated at the touch of a button. Everything – the article adds – can be assembled in just three minutes.

There is a 'catch' though: the wheelchair user has to wear diving suit and gear.

Tests have shown the device to be safe and even able to perform underwater somersaults.

More optimism

In the Russian MS Society's interpretation, this invention will not necessarily turn lots of disabled people with MS into divers in wheelchairs but can enable 'unlimited' perspectives on MS mobility and rehabilitation.

The 'barracuda' underwater wheelchair, as it was appropriately named by Mr Skikevich, also has the potential to encourage further engineering feats for the benefit of people with MS and other potentially disabling conditions. At the very least, it can make those affected look forward with greater anticipation towards the summer season.

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

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Serbia: www.emsp.org/serbia

Multimedia patient advocacy

By Dragana Ilic Šutović

The Serbian MS Society (DMSS) is relying increasingly on multimedia initiatives in its outreach to different MS stakeholders, from MS patients to health authorities. Two related activities are the publication of a popular MS magazine and the development of a nationwide video campaign.

My MS World

This is the title of the Society's magazine targeting mainly MS patients but also specialists and relevant institutions.

The publication is currently printed in 3,000 copies but DMSS is receiving requests - which it can only honour through additional fundraising - to substantially increase this number.

DMSS is also producing and disseminating brochures, leaflets, guides and MS manuals.

‘I have MS’

The name of DMSS’ 2017 video campaign is meant to help reach out to the general public and convey the message that people living with MS and their families need support to improve their quality of life.

In addition, the Society’s representatives plan TV and radio appearances on this topic in order to fuel more dissemination through print and e-media as well as future debates, round-tables, seminars and press conferences.

This campaign will focus on key aspects of MS management such as treatment and rehabilitation, education, employment and mobility. But the showpiece will be MS treatment.

DMSS plans to mount ‘positive pressure’ on decision-makers in order to improve access to medicines as an important step in ensuring a better quality of life for people with MS.

Severely restricted access

The estimated MS population in Serbia is 7,000 people. Currently, less than 10 percent of them are treated with so-called immunomodulatory therapies such as interferon beta and glatiramer acetate. Moreover, for second-line treatments there is virtually no access.

DMSS considers this a serious infringement of patients’ constitutional right to be treated and calls for all stakeholders to urgently address this issue.

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

Training for MS carers

By Madeleine Cutting

The Spanish MS Society AEDEM organised two training sessions for MS carers – key but often disregarded actors in the process of MS management.

The motto of this initiative was “*Knowing how to look after oneself in order to look after others*”.

Indeed, in order to provide quality of care for their loved ones affected by MS, family members have to first acquire the necessary skills and strategies regarding their own care and wellbeing.

The training sessions took place in March and May 2016.

What is this about?

The training sessions consisted of theoretic and practical courses and were coordinated by psychologist Rosa Gómez Aguilera. She is a European Specialist in Psychotherapy and State Consultant on professional qualifications for social-sanitary assistance of dependent persons.

The outcomes were encouraging: participants received relevant certificates and a number of AEDEM branches developed similar initiatives locally.



The training sessions for MS carers were held in AEDEM's Training Centre in Madrid

Giving care

Through its contacts with people living with MS and their carers, AEDEM has learned that caring for a dependent member of the family is very taxing and carries a great amount of physical and emotional responsibility. Caring for others can be wearing but in this process MS carers should not forget to also look after themselves, advises AEDEM.

Supporters

The training courses for MS carers were held in AEDEM's Training Centre in Madrid and were sponsored by the ONCE Foundation - the National Organisation for the Blind.

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United Kingdom: www.emsp.org/uk

My MS, My Needs: 1 in 3 people without care and support

By Georgina Carr

The UK MS Society's My MS, My Needs 2 survey of over 9,000 people with MS in England shows that demand for social care among people with multiple sclerosis has increased. Despite this reality, fewer are getting the support they need.

Worse situation

The second edition of this survey - completed in 2016 - shows that 1 in 3 people with MS who need help with essential everyday activities such as washing, dressing and eating are not receiving that support.

Compared to the situation captured in the first survey - published in 2013 - these new figures show that a higher proportion of people are now paying for care and relying on family and friends.



Long-term solution urgent

The UK Government recently commitment £2 billion of funding over the next three years for social care in England.

The UK MS Society’s Chief Executive Michelle Mitchell says that the funds allocated will only address the challenges faced by people with MS in the short-term:

“We welcome the Government’s investment in social care. It will help in the short-term but social care desperately needs long-term funding to improve the system for people who rely on it. A solution that works for older and disabled people, including those with MS, must be found before the end of this parliament.”

According to the [Atlas of MS](#) database there are around 100,000 people living with MS in the UK. 90,000 of them live in England.

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