

EMSP Web Alert

June / 2012



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This year, the EMSP's Annual Congress (Barcelona, 19 and 20 May) focused on the latest scientific developments and offered the 130 participants an excellent opportunity to exchange ideas and experiences.

John Golding, EMSP President, warmly welcomed the Congress participants and gave the floor to Josep Lluís Cleries i Gonzàlez, the Minister of Social Welfare and Family of the Catalan government. The Minister reaffirmed his political support to persons with MS and other chronic diseases.

The Congress opened with an update by Prof. Thompson on new MS treatments that are in the pipeline. Mar Tintoré explained the impact of female hormones, pregnancy and breastfeeding on MS. Prof Catherine Lubetzki described the progress being made in remyelination research. And the management of MS symptoms using cannabis was presented by Prof. Patrick Vermersch.

In the afternoon, participants joined one of the four workshops which covered topics such as the European register for MS (EUREMS), certified online training for MS nurses in Europe (MS NEED), the barometer and its journalistic translation "UNDER PRESSURE", and the case management project on job retention for persons with MS.

EMSP Annual Congress 2012



On Day Two of the Congress, the participants learned about national political developments in health and social care since 2003 in Serbia thanks to a presentation by Irena Dujmovic Basuroski. María Concepció Tarruella Tomás, Deputy for Lleida, emphasised the fact that politicians are not fully aware of all aspects of the issue. It is the responsibility of all citizens who know about MS to raise public awareness. Moreover, it is important to also bear in mind that the message to politicians is clearer when it comes from a union between medical professionals and patient organisations. Jorge Da Silva informed the audience about the drastic cuts made to the health budget in Portugal and the impact on persons with MS. Luiza Wieczynska shared the Polish MS Society's strategies to empower persons with MS and to lobby at national level.

The EMSP Secretariat would like to thank all of the speakers, moderators and participants for making the EMSP Annual Congress a great success – and it looks forward to meeting everyone again next year.

Presentations from the 2012 Annual Congress are available online at www.emsp.org
A conference report is currently being drafted and will be available soon.



EMSP Youth Congress 2012

The third EMSP Youth Congress was a really unique opportunity to discuss the specific needs and expectations of Young Persons with MS (YPwMS) and to share information about projects and activities in different countries across Europe.

In accordance with the recommendations from the 2011 Youth Congress, this year the two themes discussed were sexuality and pregnancy.

Emma (Ireland), who is the YPwMS co-opted to the EMSP Board for the next two years, warmly welcomed the participants.

The Congress opened with the showing of a video dealing with the sexual life of persons with MS and the fears faced by women who wish have children. The participants were very touched by the movie, as it reflects their personal experience. This video, created with the support of YPwMS and EMSP, is now available on the EMSP website: www.emsp.org

Marjan (the Netherlands) moderated the session on sexuality, which is naturally a delicate and intimate topic. Participants shared their experiences and strategies for facing sexual issues, with the discussions sometimes being leavened by peals of laughter.

The session on pregnancy was moderated by Isabella (Belgium). Participants could hear from Camille (France), who is five months' pregnant, and Stephanie (France), who had a child after having been diagnosed.

Federica (Italy) presented the activities relating to sexuality and pregnancy of the Italian MS Society. The audience found her speech to be very inspiring, and the participants left the room full of ideas and energy and looking forward to meeting up again next year.





India



Korea

A global success

World MS Day 2012 was a great success with activities taking place in more than 75 countries worldwide. People with MS, their friends, family and medical professionals, all used their imagination to raise awareness of the disease amongst the public.

In Australia people kissed goodbye to MS, whilst in Canada and the USA Niagara Falls changed colour (orange on the USA side of the border and red on the Canadian side) to mark the day. In Egypt people with MS held a chess tournament to raise awareness, and in the United Arab Emirates the largest man-made neurone (more than three metres long!) was on display at Mirdif City Centre Mall in Dubai. In Japan local volunteers took to the streets to hand out leaflets about MS, while in the Netherlands outdoor advertisements from the 'What am I?' campaign were placed at bus shelters and stations in six cities around the country. Diverse activities represented the diverse cultural and social environments in which people with MS live all over the world.

Bringing World MS Day to new audiences

Raising public awareness of MS is crucial to making positive changes to the lives of people living with the disease. Raising funds for research and care, addressing discrimination in the workplace and advocating for policy change with decision makers all rely on some prior awareness and understanding of MS. For this reason MSIF, along with the international working group, made up of communications and campaigns experts from eight countries around the world, created a campaign that would enable people with MS to do the talking and share their stories with a wider audience.

As well as reaching thousands of people around the world through events and national activities, the World MS Day campaign reached thousands more online through the international website, social media and press. More than 50,000 people visited the World MS Day website in the month of May and more than 214,000 people were reached with WMSD messages through facebook during the week of World MS Day 2012. Of these more than 190,000 were outside of MSIFs usual audiences.

Living with MS

The theme for 2012 was 'Living with MS' which aimed to create a dialogue between people with MS and the public. Throughout the month of May people with and affected by MS were



Japan

invited to create digital postcards that highlighted what living with MS meant to them. The postcards went live on 30th May in an interactive wall and map filled with inspirational photos and videos. So far more than 2,200 stories have been uploaded. If you haven't managed to create a postcard yet don't worry, you still have until July to share your ideas with the world. Visit www.worldmsday.org to meet the 1000 faces of MS and to become one of the faces yourself.

What am I?

A second campaign ran simultaneously throughout the month of May and aimed to raise awareness of three key messages about MS through riddles released online in the run up to World MS Day. These were supported by press, radio, print and outdoor adverts. The riddles, written from the perspective of MS, were produced in English, French, Spanish, German, Portuguese and Arabic and have reached more than 31,000 people on youtube since the campaign launch on the 9th May.

To watch the riddles and share them with your friends, family and colleagues, please visit the World MS Day [Youtube channel](#).



Cairo



Yemen



The Netherlands

UNDER PRESSURE exhibit attracts shoppers in Estonia

The powerful images of the UNDER PRESSURE project grabbed the attention of shoppers at the Solaris Mall in Tallinn, the capital city of Estonia. Located at the crossway of a cinema, a bookshop and a restaurant, a steady stream of traffic passed through the exhibit for the entire week of 30 May to 6 June. Rough estimates suggest that more than 3 000 people stopped to view some images, while approximately 700 took the time to carefully read the captions, thereby learning about the situation for PwMS in Estonia as compared to other EU countries.

The Society was pleased to involve and engage policy makers and other stakeholders. Merike Martison, the Deputy Mayor of Tallinn gave a speech at the opening event. As access to social services is low in Estonia – particularly for PwMS who have family – it was noteworthy that Ms. Maripuu commented specifically on the high quality of life evident in the photographs from Iceland. Genadi Nikolajev of Novartis, who recently issued the application for reimbursement of Gilyena to Estonian Health Insurance Fund and Silja Rebane of Richter Gedeon/Biogen, who's similar application for Tysabri is waiting for approval for the fourth year, also attended. At present, both Gilyena and Tysabri remain unavailable, primarily for financial reasons according to the Ministry of Social Affairs.





“We were extremely glad to have the author of this magnificent project, Marilyn Smith, with us for the opening on 30 May,” says Pille-Katrin Levin, Chairwoman of Union of Estonian MS Societies. “I’m also grateful to our members and volunteers, who passed out information pamphlets about MS and encouraged shoppers to participate in “hidden symptom” simulations to better understand life with MS.”

A highlight of day was the opportunity for any shopper to challenge Harry Kestlane to a game of chess. A cartographer by training but blinded by a relapse several years ago, Harry uses his mapping skills and memory to track the game. Remarkably, Harry rarely losses his place – or the match. As Harry and other older PwMS in Estonia spend many days isolated at home, the event was a nice opportunity to see each other and interact with people who may have misconceptions about living with MS.

Similar activities were carried out in Tartu, the second-largest town in Estonia. Members of the MS Society also gave press interviews (TV and radio) in both cities.



In April, with the support of EMSP's MS Champion, the Romanian MEP [Petru Luhan](#), EMSP held two events at the European Parliament: the exhibition "UNDER PRESSURE" and the MS Information Day.

UNDER PRESSURE is a multimedia project that explores how national health and social policies influence – *for better or worse* – the experience of living with MS in Europe. It features pictures that were taken by five world-class photojournalists: Walter ASTRADA, Lurdes BASOLI, Maximiliano BRAUN, Fernando MOLERES and Carlos SPOTTORNO. Over a 10-day period, they followed persons with multiple sclerosis in a variety of settings, with the aim of ultimately showing the contrast between countries in terms of: general conditions and specialised facilities for health care and rehabilitation; the ability to live at home (including adaptation measures) or having to reside in a care facility; the possibility of remaining in the workforce (including adaptation measures) or being unemployed and perhaps forced to live on social assistance; and how daily living situations make multiple sclerosis more/less difficult in relation to other countries.

EMSP Information Day and Under Pressure Exhibition in the European Parliament



EMSP had the honour of displaying twenty pictures from UNDER PRESSURE inside the European Parliament for several days. It was a wonderful opportunity to raise awareness on the quality of life of persons with MS in Europe and their difficulties in accessing treatment in certain countries. Romanian MEP [Petru Luhan](#) reaffirmed:

“There is a definite need for action at the European level, in the interests of European citizens, in order to eliminate the disparities in access to diagnosis and treatment that exist in Member States.”

During the MS Information Day, Elisabeth Kasilingam, EMSP project coordinator, presented the results of the MS Barometer 2011. Her presentation confirmed the existence of health inequalities between European countries. Lenka Pospíšková, Charles University of Prague, presented the negatives consequences of delayed treatment for persons with MS.

Matic Meglic from the Slovenian Health Institute presented the database PARENT, which strives to rationalise and harmonise the development and management of patient registries, thus enabling analyses of secondary data for public health and research purposes. Prof. Tim Friede, University Medical Center of Göttingen, presented the European MS Register (EUREMS).

Finally, Marilyn Smith introduced Maximiliano Braun, Lurdes Basoli and Carlos Spottorno themselves. These three photographers from the UNDER PRESSURE project shared with the audience some of the experiences they had following persons with MS in the different countries for over a week.



Estonian MS Round Table



Estonian MS Round Table Discusses Estonia's Low Score in MS Barometer

On April 3, 2012 the Union of Estonian Multiple Sclerosis Societies (ESMÜL) hosted a round table of discussions on the quality of MS treatment and services in Estonia and the scope for improving them. While the round table came up with no solutions for subsidising the Natalizumab treatment - the most pressing problem for Estonian MS patients - a number of smaller steps for improving the quality of life for people with MS were agreed.



The participants of the round table included Mr Hanno Pevkur, Minister for Social Affairs of Estonia, representatives from the National Health Insurance Fund, members of the Social Affairs Committee of the Estonian Parliament, and members of the Neurologists' Union of Estonia. The round table was initiated and moderated by the Estonian Multiple Sclerosis Union and the European Multiple Sclerosis Platform.

The round table event began with presentations from EMSP president John Golding and Secretary General Christoph Thalheim, who introduced Europe-wide MS projects and the results of the MS Barometer survey. Estonia scored low in most categories of the MS Barometer. Golding and Thalheim suggested that Estonian authorities focus on ensuring employment for people with MS, building an MS Registry and adopting a more holistic approach to budgeting. They emphasized that keeping young people active by providing them with immediate treatment is in the long term less costly for society.

Dr Katrin Gross-Paju, the founder and manager of the MS Centre at West Tallinn Central Hospital, talked about the accessibility of MS treatment. According to her, the situation was currently good. Interferone treatment was available and fully subsidised for all patients. But as this has been the case only since 2004, many patients had previously been treated with third-choice medications which had caused severe side-effects. There were also regional inequalities in access to specialized treatment. Even more limited was access to rehabilitation, which is not tailored to the needs of MS patients and not fully subsidised.

A major part of the discussion was devoted to the availability of second-choice medications. No such treatments are currently subsidised for patients. The Chairwoman of ESMÜL, Pille-Katrin Levin, emphasized that patients were expecting a choice to enable them to have the best possible treatment. Those for whom the interferone treatment was not effective currently had no other options. Natalizumab, for example, had not been admitted to the subsidy list.



According to Erki Laidmäe, the representative of the Estonian National Health Insurance Fund, there was a lack of studies comparing the effects of Natalizumab on other treatments. Due to this and other factors, the current verdict was that subsidising Natalizumab would not be cost-effective. Minister Pevkur added that dozens of new treatments were awaiting subsidy, and that cost-effectiveness was therefore a vital consideration.

On the positive side, the Minister said that the whole system of disabilities and rehabilitation was currently being reformed. The new system would be more focused on keeping people employed or getting them back to work. He encouraged the MS Society to work together with other patients' unions in educating employers about chronic illnesses and the possibilities of enabling people with MS to keep working.

All participants recognized the importance of MS Registry and decided to start working towards creating such a database after a relevant European pilot project is completed.

Additionally the Social Affairs Committee of the Estonian Parliament invited the Estonian MS Society to discuss relevant issues at a committee meeting.



European Medicines Agency boosts EU transparency with online publication of suspected side effect reports

Member States and the Agency release data on medicines in compliance with EudraVigilance access policy

The European Medicines Agency has today begun publishing suspected side effect reports for medicines authorised in the European Economic Area (EEA) on a new public website: www.adrreports.eu. The reports come directly from the European Union (EU) medicines safety database EudraVigilance, and are one of the many types of data used by regulators to monitor the benefits and risks of a medicine once authorised. The launch of the new website is part of the Agency's continuing efforts to ensure EU regulatory processes are transparent and open and is a key step in the implementation of the EudraVigilance access policy.

The information published today relates to approximately 650 medicines and active substances authorised through the centralised procedure, which is managed by the Agency. Information on the website is presented in the form of a single report per medicine or active substance. Each report pulls together the total number of individual suspected side effect reports submitted to EudraVigilance by Member States and marketing authorisation holders. These aggregated data can be viewed by age group, sex, type of suspected side effect and by outcome. Within a year the Agency aims to additionally publish suspected side effect reports for common drug substances used in nationally authorised medicines.

A side effect (also known as an adverse drug reaction) includes side effects arising from use of a medicine within the terms of the marketing authorisation as well as from use outside the terms of the marketing authorisation, including overdose, misuse, abuse and medication errors, and those associated with occupational exposure.

All information on the website relates to suspected side effects. Suspected side effects may not be related to or caused by the medicine, and as a result, the published information cannot be used to determine the likelihood of experiencing a side effect or as an indication that a medicine is harmful. All users of the website are asked to read and accept a disclaimer explaining how to understand the information before they view a web report.

Medicines are an important part of modern healthcare, providing effective treatments for many diseases and conditions. For a medicine to be authorised for use in the EU the benefits of the medicine must always outweigh the risks.

The European Medicines Agency is a decentralised agency of the European Union, located in London.

The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union.

Launch also highlights the importance of side effect reporting and pharmacovigilance in safeguarding public health within the European Union. Side-effect reporting is a key element in ensuring the detection of new or changing safety issues, and the Agency continues to further strengthen its work with partners and stakeholders across Europe to ensure a robust system for safety signal detection.

In June, the Agency will launch the website in the remaining 22 official EU languages.

More information on the work of the European Medicines Agency can be found on its website: www.ema.europa.eu



European Patients' Rights Day

Active Citizenship Network's mission is to promote and support the construction of the European citizenship as an "active citizenship" which means the exercise of citizens' powers and responsibilities in policy-making.

Active Citizenship Network celebrated the 6th European Patients' Rights Day in Brussels, with a conference entitled "Active Ageing citizens at the center of EU health policy", last 15th and 16th of May 2012.

The conference was fully focused on the European topic of the year "Active Ageing and Solidarity between Generations". Insofar as the number of ageing citizens is rapidly increasing (Europeans aged 65+ is expected to increase by 45% between 2008 and 2030, and even further to over 30% of the population by 2060) the issues of their access to health care services and the respect of their rights as patients are becoming central and extremely challenging.

The objective of the conference was thus to demonstrate that part of the solution resides in a change of perspective vis-à-vis ageing citizens, from weak patients into "empowered users" of health care services, able to contribute to a better implementation of their rights.

Best practices on Active Ageing citizens in health policies have been presented and discussed. The BP focused on what healthcare services, civic associations and governments are doing in this area to reveal the concrete benefits of this approach.

During the conference, the Vice-President of the European Parliament said that we must manage the crisis but, at the same time, safeguard the patients' rights and the European welfare state. The economic and social crisis that we are experiencing does not limit the ability to work together in networks and to make alliances. In this way we are already saving the European welfare state, we are already innovating it. Experiences show that helping people and improving their quality of life can be easy, quick and not expensive.

The Best Practices report "Active ageing into practice! Experiences of civic engagement in health policies" is available on the following link:

www.activecitizenship.net/files/take_action/active_ageing_eu_policy.pdf.

