EMSP Web Alert

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This kick-off meeting for the European Register for Multiple Sclerosis (EUReMS) (4 July, Luxembourg) brought together all project partners and a representative of the Executive Agency for Health and Consumers. Described as “a tool to assess, compare and enhance the status of people with MS throughout the EU,” EUReMS is a three-year project co-financed by the European Commission (EC) under the Public Health Programme.

The EC has expressed its intent to tackle more effectively existing inequalities in health care across the European Union, focusing on: provision of health services, design of health promotion, health protection activities, and living and working conditions. The Commission will also seek to develop successful strategies to: improve data collection, monitor health inequalities, prioritise areas of improvement, and identify best practices that can be shared among EU countries.

Reflecting these EC goals, the EUReMS project addresses the current lack of data – at European level – on treatment and care of PwMS. EUReMS aims to provide comparable and reliable data on MS, and to assess the long-term effects of disease-modifying drugs on the development of MS.

Six core principles underpin the EUReMS project:

- Build on existing national or regional data collections;
- Involve and combine the expertise of clinicians, researchers and patient organisations;
- Address questions and concerns at international level;
- Include the highest available expertise to develop technical solutions;
• Improve access for all European PwMS to evidence-based healthcare services; and
• Offer a cutting-edge research tool to gain further insights into various aspects of MS.

To capitalise on diverse knowledge and expertise, EUReMS brings together partners from various academic, scientific and patient organisations including: Association of MS Societies of Croatia; Department of Neuroscience in the University of Sassari, Italy; DMSG, Bundesverband e.V., Germany; Karolinska Institutet, Sweden; MS Centre of Catalonia, Spain; Multiple Sclerosis Society, UK; Neurological Rehabilitation Center Quellenhof, Germany; Polish MS Society, Poland; Romanian MS Society, Romania; University of Bergen, Norway; University Medical Center Göttingen, Germany; and University Medical Center Göttingen, Germany. As the lead partner, EMSP will coordinate activities and implementation.

The key outcomes expected as EUReMS is developed are:

• A critical mass of national/regional MS centres for collaborative and sustainable European research in the field of MS;
• An IT platform for collaboration and dissemination of information on MS; and
• Contribution to new EU policies.

These positive results would ultimately serve to improve knowledge of clinicians and support better care through the implementation of a quality management policy for diagnosis and management of MS. The project will also increase the sense of community for PwMS and their families, and raise awareness of the disease among the general public in the European Union.

For more information on the EUReMS project, please visit EMSP Website.

Multiple Sclerosis Information Dividend (MS-ID) project

Through the MS-ID project (2007-2009), co-funded by the European Commission under the Public Health Programme, EMSP demonstrated the feasibility of an pan-European register for MS – the critical first step towards developing a vital tool for all MS stakeholders.

www.ms-id.org
On July 1, 2011, the MS NEED steering committee met in Frankfurt to review key successes and learning to date of the MS NEED (Multiple-Sclerosis Nurse Empowering EDucation).

Launched in 2009, the MS-NEED’s objectives were:

- Understanding the role of the MS nurse in Europe
- Identifying areas where the MS nurse role can be changed or expanded to improve patient quality of life
- Raising awareness on the role(s) and identifying best practice for education, certification, training and tasks of MS nurses
- Promoting the need for comprehensive services to PwMS by MS nurses across Europe

The study, polling 280 MS nurses in six countries (Czech Republic, Finland, Germany, Italy, Poland, and United Kingdom) found considerable variations in the availability of specialized training and education for MS nurses across Europe. There are gaps in services, training and education opportunities among nurses requiring immediate attention to avoid inequalities in patient care.

Led by Anne Winslow, Vice-President of EMSP, the steering committee agreed to develop a European Consensus to broadly define the MS nurse role and make a case for best practice based on training programs at national level. The European Consensus will be used to facilitate communication with the statutory bodies, and as a lobbying tool. It should: highlight the value MS patients place on MS specialist nurses and the potential economic impact of specialist care, set foundations and steps to inspirational goals and highlight resources needed. The European Consensus is expected by the end of 2011.
Over the summer, Julie Deléglise, EU Affairs and Membership Officer, was warmly welcomed by the headquarters of three EMSP members: the Polish MS Society (Polskie Towarzystwo Stwardnienia Rozsianego), and the both of the Spanish societies, the Asociación Española de Esclerosis Multiple (AEDEM-COCEMFE) and the Federación Española para la Lucha contra la Esclerosis Múltiple (FELEM). It is a point of honour for EMSP to be close to its members, and of great importance that EMSP understand their respective needs and expectations.

During the meetings, Julie provided information on current EMSP projects and activities at European level. National initiatives, such as fundraising activities and lobbying, were also discussed, as well as potential future collaborations.

One fundraising activity in particular has been a great success in Spain. In 1994, FELEM launched a social awareness and fundraising campaign called “Mojate,” which translates as “get wet for MS.” Participants obtain sponsorship for swimming lengths. The 17th annual event, held on 8 July 2011, was another major achievement. In recent years, the campaign raised over EUR 604 700 and participants collectively swam more than 58 202 000 metres. Mojate now involves over 900 participating pools and beaches, and FELEM produces merchandise that is sold to raise more money to support research and improve the quality of care of PwMS. The Mojate campaign attracts media attention and raises public awareness of MS.
On 6 and 7 July 2011, Christoph Thalheim, Secretary General of EMSP, met with members of the Serbian MS Society to discuss ways of addressing the lack of access to latest disease-modifying therapies. Dr. Jelena Drulovic, Chair of the Medical Advisory Board, and Jasmina Brajkovic, President of the Serbian MS Society, were among those present to discuss this key concern of Serbian PwMS.

After updating Christoph on current and upcoming work priorities, the Serbian MS Society expressed its desire to explore the possibility of hosting a High Level Roundtable on this key subject, in accordance with the guidelines and good practice (the so-called NHLRT Tool Box) developed by the EMSP Secretariat.

As part of his visit to Serbia, Mr Thalheim made a special trip to Atomska Banja, a spa located in the northern part of the Cacak-Kraljevo ravine that is renowned for the healing properties of its natural spring water. The spa also specialises as a rehabilitation centre for PwMS: some people have been visiting annually for the last 40 years. In addition to the proven positive effects of the spa’s various therapies for MS, visitors are drawn by the beautiful nature and numerous cultural monuments surrounding the village of Trepca.

Manuela Wirth (person with MS):

“I met Dr. Lidija Obradovic - Bursac and Mr. Borivoj Jakovljevic in Brussels in May at the EMSP Conference and they invited me to come to Serbia. My daughter and I stayed one week in August at the Atomska Banja Spa. I received all the therapies, hydrotherapy with the "magical" thermo mineral water, and massages.....

When I came to the Spa I brought a full bag of medicines, and surprisingly I did not need it. Usually, I have migraine and stomach problems but not in Serbia! The week in Serbia was a great experience, I felt much better after these six days. Hospitality and the friendliness are key to Atomska Banja Spa”.

Atomska Banja has recently been renovated to western standards, and will open a brand-new accommodation and therapy centre later this year.

For more information: www.atomicspaserbia.com
The European Medicines Agency (EMA), in close cooperation with the United States Food and Drug Administration (FDA) held a two-day workshop at the EMA offices in London on drug-related progressive multifocal leukoencephalopathy (PML) on 25-26 July 2011. The purpose of the meeting was to bring together experts and stakeholders of PML to identify research questions that will address knowledge gaps in order to reduce the burden of the disease.

Some of the medicines associated with PML bring major benefits to large numbers of patients. As a result effective ways to manage the risk of PML through identification of patients at risk as well as early diagnosis and treatment of PML are of major public-health importance. Medicines regulators in Europe and the US are therefore taking a leading role in shaping the research agenda to broaden the knowledge base for medicines regulation, thereby contributing to better public health protection.

Some 170 experts and stakeholders from regulatory authorities, research funding bodies, academic and clinical researchers, patients and healthcare representatives and industry discussed a common way forward for research in drug-related PML, including possibilities for funding and partnerships, and mechanisms for information sharing. Mr Christoph Thalheim was invited as speaker and co-moderator, to represent the patients’ view by an opening speech and some closing remarks at this high level event. His speech was prepared in close consultation with MS patients and caregivers, some of which are suffering from the devastating impact of PML. Christoph briefly described the growing importance of the patients’ input to ongoing health care discussions and decisions and elaborated the difficulty to identify the right balance of benefits versus risks when deciding for or against a highly effective therapy coming known risk of severe disability or even death.

While the workshop was focused on PML, it was acknowledged that this type of collaborative research model could become a blueprint for research into other drug-induced diseases.

The immediate follow-up to the workshop will include finalising a research agenda on PML and its dissemination to funding bodies and the research community, as well as fostering further partnerships and research collaboration.

For more information and presentations of the workshop, please consult: www.ema.europa.eu

Reducing the burden of PML

PML is a rare, debilitating and sometimes fatal disease that is characterised by progressive damage to the white matter of the brain. It is caused by the JC virus. PML can occur in different conditions that affect immune response and it has been identified as an adverse drug reaction to some medicines that affect immunological functions.
Under Uhuru Peak, Kilimanjaro, Tanzania, Africa – July 18, 2011 – Today, seven adventurous men and women with Multiple Sclerosis (MS) and four with Parkinson’s disease (PD), along with nine climbing companions, reached the highest peak in Africa. This climb clearly demonstrated that neurodegenerative diseases do not represent the end of ‘normal’ life, but that people living with the diseases can in fact go on to achieve staggering feats. Mount Kilimanjaro in Tanzania stands at 19,340 feet, not only making it the highest peak in Africa, but also the highest free-standing mountain in the world.

“This ‘Kilimanjaro Leap of Faith Adventure’ was meant to challenge the body, expand the mind and foster courage in dealing with the diagnosis of a neurodegenerative disease. There have been some really tough parts of the trek, especially altitude sickness, for which there is nothing you can do. Imagine that on top of our neurodegenerative diseases. But, we’ve made it and that’s a credit to all of us who believe that we can go beyond the limitations of our disease and still achieve incredible results, both physically and mentally.” said trip organiser Lori Schneider, founder of Empowerment Through Adventure.

The Spanish MS Society, FELEM, supported the participation of Inés Grau in this adventure. She is 24 years old, and was the youngest of the team, Diagnosed when she was 17, Inès has been proactive in the MS cause. She is involved at European level and was a moderator at the EMSP Youth Congress 2011 in Brussels.
The Kilimanjaro climb has certainly had its challenges. Some have suffered from altitude sickness, occasionally worsened by the symptoms of their neurodegenerative disease. It is for this reason that three people with MS and five of the climbing companions did not reach the summit. However, everyone has assisted and supported each other every step of the way. EMSP congratulates all adventurous men and women who have gone beyond their limitations to redefine who they are and what they are capable of achieving.

Lori Schneider is a professional speaker and mountain climber living with MS. Lori carried the flag for the first ever World MS Day to the summit of Mt. Everest, becoming the first person with MS to complete the Seven Summits. Lori now leads others with MS on adventure activities, inspiring them to climb beyond their limits.

For further information on Lori Schneider and Empowerment Through Adventure, please visit: www.EmpowermentThroughAdventure.com.

Kilimanjaro Photos courtesy of photographer Jeff Rennicke.
EMSP will be represented at the:

ECTRIMS/ACTRIMS
5TH JOINT TRIENNIAL CONGRESS
19 – 22 OCTOBER 2011, AMSTERDAM, NL

During this event, EMSP will hold a Stakeholders Forum in the framework of its newly launched EUReMS project.

For more information on the ECTRIMS congress, please visit: www.congrex.ch/ectrims2011

For more information on the EMSP Stakeholders Forum, please contact EMSP Secretariat.