EMSP Web Alert

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In this issue

- EMSP Annual Congress 2011 in Brussels
- Second EMSP Youth Congress
- World MS Day in Austria, Estonia, Netherlands and Norway
- Climbing Mount Toubkal
- A new therapy option available soon for PwMS with mobility impairment
- Promoting accessibility and mobility for all persons with disabilities
This year, EMSP’s Annual Congress (Brussels, 12 and 13 May) focused on assistive devices and technologies, but also provided news on the latest developments in disease modifying therapies (DMTs), the importance of patient input for health technology appraisals in the European Medicines Agency, new treatment and management strategies for MS symptoms. The Congress attracted 120 participants from all over Europe.

The Congress opened with updates on aspects of therapy for PwMS. Mr Juan García Burgos of the European Medicines Agency (EMA) discussed the importance of patient input for the work of EMA: patients are most directly affected by new developments in medicine and can provide a real-life experience of the disease and its current therapeutic environment. Prof. Michel Clanet, President of ECTRIMS (European Committee for Treatment and Research In Multiple Sclerosis) highlighted the latest developments and risks in innovative DMTs, including both oral and non-oral treatments. Prof. Norbert Goebels, Department of Neurology Heinrich-Heine University, presented two new options to treat spasticity and loss of mobility.

Assistive technology (AT) is garnering attention in the EU, appearing on the agenda of the European Disability Strategy (EDS) 2010-2020. Gert Jan Gelderblom, President of the Association for the Advancement of Assistive Technologies (AAATE), addressed the need to think beyond wheelchairs, crutches and scooters. In its broadest sense, AT is understood as any product- or technology-based service or solution that enables people of all ages with activity limitations in their daily lives – work, education and leisure. Occupational therapist Marijke Duportail of the National MS centre in Melsbroek (Belgium) explained how the growing Design for All philosophy is influencing architecture and interior design, and provided concrete examples of
workplace adjustments and ergonomical solutions to improve general accessibility, posture and energy efficiency, thereby reducing fatigue.

Emma Chappel, urology nurse, discussed the medical benefits of intermittent self-catheterisation (ISC): the most effective solution for complete bladder emptying, ISC enables individuals to carry out their normal, daily activities with confidence. Daniel Cooper, a PwMS from the UK, shared his positive personal experience with self-catheterisation. Angela Smith Davies, research physiotherapist at the MS Research Unit in the BrAMS Centre (Bristol, UK), presented examples of emerging medical devices being developed there.

Day Two of the Congress allowed participants to join four workshops which covered topics such as the importance of symptomatic treatment options, successful fundraising initiatives, sustainable relationships with donors and patient involvement in health technologies assessments.

The Gala Dinner was an obvious highlight, with a moving performance by Manuela Wirth (in the photo), semi-finalist from “Super Talent Germany 2010”. Guests enjoyed the opportunity to talk together over a lovely dinner and danced the night away.

The EMSP Secretariat thanks all speakers, moderators and participants for making the EMSP Annual Congress a success – and looks forward to meeting everyone again in Barcelona on 19-20 May 2012.

All presentations from the 2011 Annual Congress are available online at www.emsp.org; a conference report is currently being drafted and will be available soon.
Following the great success of the first Youth Congress in 2010, the second EMSP Youth Congress took place on May 12th 2011 in Brussels.

The EMSP Youth Congress is a really unique opportunity to discuss the specific needs and requirements of Young People with MS (YPwMS), and to share information about projects and services in different countries across Europe.

There were four subjects in particular the twenty participants from all over Europe were asked to discuss:

- **Information about MS.** Discussions took place around how young people access information about MS in different countries. There was debate around the kind of information that YPwMS are looking for and the difficulties YPwMS face when looking for information.
- **Networking for Young People with MS.** The importance of networking through both social media and face to face interaction for YPwMS was discussed. The dialogue included how to set up such networks, how to maintain and monitor these networks and what the networks could achieve.
- **YPwMS and MS Societies.** The focus was on how each Country’s MS Society involved YPwMS. There was further discussion about what YPwMS expected and actually needed from their MS Society.
- **Fundraising by YPwMS.** Discussions took place about the kind of activities that YPwMS want and how these should be financially supported. There was debate about how and to what extent the MS Society could be involved.

The discussions were broad, enthusiastic and gave everyone a chance to hear of the experiences in other nations. YPwMS’ lives are all enriched when they share ideas and create the energy for positive change in our respective countries. The energetic discussion and relationships begun in 2010 have continued in Brussels. Now the EMSP and all participants have an opportunity to work together and improve the lives for all Young People with MS.
World MS Day in Austria

To celebrate World MS Day, the Austrian MS Society organised a one-day programme for PwMS. A plenary discussion involving the Minister of Social Affairs, Rudolf Hundstorfer, created an opportunity for dialogue among PwMS, medical personnel and government authorities. The event also included engaging workshops focusing on four relevant topics: Changing your lifestyle; Influence of psychological factors; News concerning immunotherapy; and Sports and rehabilitation to improve mobility.

The Society’s objectives for this day were threefold: to provide information on recent medication, therapies and support for PwMS; to strengthen awareness of the needs of PwMS; and to allow PwMS, their relatives and caregivers to share personal their experiences.

Over 300 people from all over Austria attended the event, which took place at the Hotel Marriott in Vienna on 28 May 2011. Invitations were sent to regional MS societies and support groups, and announcements were published in the Austrian MS Society’s journal and on the website (www.msgoe.at), thus reaching a large public.

World MS Day in Estonia

The Estonian MS Society hosted its first official event to celebrate World MS Day in Freedom Square, Tallinn. On 25 May 2011, an enthusiastic group of YPwMS and volunteers set up a large tent, hoping it would shelter the group while they worked as MS ambassadors and information agents. Although there was neither too much sun nor rain, strong winds ripped through the tent and blew the brochures and leaflets all across the square. Embracing the whims of nature, the volunteers used the need to chase their paperwork across the square as a chance to interact
with more passers-by. After all, the main goal of the event was to spread information about MS and the Estonian MS Society.

Many people indicated that they deliberately came to visit the tent after hearing about the Society on national radio the day before, or seeing the news programme earlier that morning. This media exposure created excellent opportunities to inform the public at large of the Society’s actions: some people came to join the Society while others came because they knew someone with MS. The tent was also equipped with “hidden symptom simulators” that allowed people to physically sense how MS symptoms change the experience of using everyday objects. These simulators showed how the disease alters or impedes activities: walking with flippers and a weight band tied around one leg; writing with thick rubber gloves; looking through thick high-prescription glasses; or trying out a wheelchair. Giving a concrete understanding of the physical symptoms of MS was fun but also revelatory. Fun is often the best way to broach serious subjects and these activities made the event educational, accessible and memorable.

Popular Estonian pop rock band Dagö gave a charity concert in the evening; many PwMS were able to attend, as the venue was very accessible. The concert was a huge success,
raising over EUR 1 000, and everyone had a terrific time.

Other events to celebrate World MS day were held in various parts of Estonia: the local society in Pärnu organised an MS Walk, for example. These local and national celebrations garnered a lot of attention in the press and helped increase membership. After such a successful and inspiring day, the Estonian MS Society certainly plans to continue the tradition next year.

**MS Youth Day 2011 in the Netherlands**

Building on the success of their MS Youth day in 2010, the Dutch MS Society (MS Vereniging Nederland) organised the second annual MS Youth Day on 21 May 2011. Events like these bring together YPwMS and their families, friends, and care team; they provide an excellent opportunity for YPwMS to exchange general information as well as their personal experiences.

A wide variety of information booths filled the field at the Soccer Stadium of FC Twente in Enschede. YPwMS were able to wander the aisles and learn about rehabilitation centres, various MS organisations, tools, books and incontinence materials. But exhibits were not all or only about MS; some booths featured fun things such as jewellery, make-up and hair advice, and tasty food tips.

Maaike Jansen, finalist television programme So You Wannabe a Popstar in 2007 tried to get the people in the plenary hall swinging, after which Myra Koomen, vice-mayor of Enschede, officially opened the MS Youth Day 2011.

Neurologist Dr. J. Nihom discussed which medications are currently prescribed for MS, what research is being done, and what new medicines will be coming on the market in the near future. He also touched on the topic of chronic cerebro-spinal venous insufficiency (CCSVI) treatment, saying simply that “This isn’t a solution”. MS Vereniging Nederland has created a card with tips to help patients keep control during conversations with
their healthcare providers, and Dr. Nihom said that though this is a handy tool, as a neurologist he too wants to manage decision-making.

A number of workshops were on offer during the afternoon programme: some were related to MS or other chronic illnesses, such as "The effects of MS on the bladder" and "Top sports opportunities with MS". But there were also various general interest topics, such as "Do something crazy", "You will regret the things you haven't done" and "More sense in your day".

After the informative and educational afternoon session, participants were invited to relax and enjoy a fashion show organised for and by YPwMS. In addition, a lottery with many exciting prizes such as shopping bags, wine and Signed ball and t-shirt from soccer team FC Twente on offer raised both attention and funds.

Yelle Nuse, Executive Director of MS Vereniging Nederland closed the second MS Youth Day, thanking everybody for their presence and giving special mention to Sander Oord and Astrid Slettenaar, whose efforts and commitment made this day another huge success.

**World MS Day: Paediatric MS the focus of international conference in Oslo**

In honour of World MS Day, the Norwegian MS Society held a conference (25 May 2011, Oslo) focusing on paediatric MS, which attracted about 50 paediatricians, neurologists and MS nurses from all over Norway.

Prof. Brenda Banwell, the keynote speaker, is director of an MS paediatric clinic at The Hospital for Sick Children (Toronto, Canada) where she treats about 100 children with MS and 250 who have had a first demyelinating attack. Prof. Banwell discussed how many doctors do not consider MS as a possibility when a child presents with typical symptoms of vision loss, headaches, numbness or balance problems. As a result, many children with MS are not diagnosed promptly and years are lost in which they could be having vital treatment. This lack of recognition of MS in children makes it impossible to accurately assess the incidence of the disease: a common estimate is 5% of the MS population, but Prof. Banwell believes the proportion is higher.

Studies show that 25% of adults believe they got MS during childhood or as teenagers but were not diagnosed until later. In recent years, Canadian specialists have been diagnosing an
increasing number of children under the age of 18 with MS. Prof. Banwell believes it is important to start treatment early: at the Hospital for Sick Children, children with MS are treated with low doses of interferons and Copaxone as well as corticosteroids. She also emphasised that children should be summoned for controls more often than adults to monitor their response to treatment.

Prof. Kjell-Morten Myhr, head of the National Competence Centre for MS in Norway, called for increased collaboration between paediatric and neurology departments in hospitals. Over the course of his 30-year career at a large hospital in Bergen, he indicated he has treated only three children with MS.

Today, the MS Society of Norway aims to inform the nation’s paediatricians, neurologists, general practitioners and MS nurses on childhood MS.
On April 16 2011, ten persons with MS (PwMS), accompanied by a neurologist, a sports doctor, physiotherapists, guides and coaches, began a climbing trip in Morocco to the summit of the Toubkal, the highest point of the Atlas Mountains at 4 167 metres.

This project aimed at honoring PwMS and also at breaking the stereotypical image of PwMS as severely handicapped.

Four days later, eight out of the ten PwMS reached the summit, tired but happy. Dr. Bouquiaux, neurologist and initiator of the project, said: “This victory is due to the exceptional mental strength of the trekkers who, in moments of doubts, were able to find the energy thanks to the strong team spirit”.

The climb was filmed by a professional film crew and produced in a first French spoken version (35 minutes). It will be made available for broadcasting later this year. The featured interviews with the PwMS are moments of great emotion and humanity.

The Belgian National MS Society, together with the regional MS societies, have given their support to this excellent initiative.

Lori Schneider, a world class climber with MS and patron of the Toubkal project, sent the following message to the climbers (www.ETAdventure.com):

“Congratulations to all! What an amazing feat for all those involved! You have proven that mental strength is as important as physical strength, when reaching our goals. You can all be proud of what has been done to help remove the labels and limitations placed upon people with MS in Belgium and around the world. My heartfelt congratulations to each member of the team, both the climbers and those behind the scenes making the event possible. If we believe, we CAN achieve!” ~Lori"

For more information visit www.msatthetopofatlas.be and website of Belgian MS Society - www.ms-sep.be
On 19 May 2011, the Committee for Medicinal Products for Human Use (CHMP) adopted a positive opinion, recommending the granting of a conditional marketing authorisation for the medicinal product Fampyra. This is a 10mg prolonged-release tablet, intended to improve the walking capacity of adult patients with multiple sclerosis with reduced mobility.

EMSP as the European voice of PwMS, is very pleased to learn of European Medicine Agency (EMA)'s recent decision, overturning their originally negative opinion on this drug. This was largely due to the positive feedback and evidence put forward by patients involved in clinical trials in Europe as well as in the US (where FDA approved the drug on the 22nd of January 2011).

The outcome illustrates again that expert's interpretation of scientific data and patients' real life experiences should be consider in tandem. The EMA confirmed that patient involvement in this process will be mentioned within relevant documents that will be published once EMA will have received the final decision from the European Commission. EMSP is proud of another acknowledgement of the importance of the patients' voice and experience.

For more details, please consult EMA website at: http://www.ema.europa.eu
Under the theme “We Want Freedom of Movement”, the 15th General Assembly of the European Disability Forum (EDF) explored all aspects of the disability movement. The event (28-29 May 2011, Budapest) attracted more than 200 participants. Julie Delégise, EU Affairs and Membership Officer, attended to represent the values and interests of EMSP.

Accessibility is essential to ensure full and effective participation in society of people with disabilities. During a seminar on this crucial subject, the Hungarian Public Foundation for the Equal Opportunities of People with Disabilities shared examples of good practice. Additionally, a representative of the Unit of Rights of Persons with Disabilities within the EC’s Directorate-General of Justice provided an overview of European laws and policies concerning accessibility.

At the end of 2012, the EC will propose a European Accessibility Act setting out a general framework for accessibility in relation to goods and services. EDF is lobbying to have the Act take form of an EU directive, thereby clearly establishing the requirements of accessibility without dictating the measures Member States must undertake to achieve it. This would give Member States sufficient freedom to take into account their national circumstances.

Accessibility encompasses many diverse aspects – ranging from information and communication technologies (ICTs) to building environments and public transportation – and must be considered a human rights issue. Accessibility allows people with disabilities to fully exercise their rights, including the right to access public buildings, hospitals and information, the right to vote, to free movement....

The creation of a European mobility card would significantly improve free movement of disabled persons, easing travel between Member States and granting the holder of the card equal status and benefits anywhere in Europe.

The financial crisis is causing alarming situations for persons with disabilities in many European countries: social benefits were cut, people with disabilities face even more difficulties to find a job...Yannis Vardakastanis, EDF President, vigorously claimed “We are not responsible for this crisis and the disability movement will fight to ensure that 80 million persons with disabilities are not the first to pay!”.

Promoting accessibility and mobility for all persons with disabilities