What you should know about MS and EMSP:

Multiple sclerosis (MS) is a complex, chronic, disabling disease, disrupting the transmission of signals in the brain. The average age of diagnosis is 20-40, a period when individuals are highly engaged in establishing their careers, raising their families and enjoying lifestyles. MS affects twice as many women as men. There are currently approximately 600,000 people diagnosed with MS in Europe each year. So far, no cure has been found.

The European Multiple Sclerosis Platform (EMSP) is the umbrella organisation for 38 MS societies from 34 European countries. EMSP represents their interests at the European level and works to achieve its goals of high quality equitable treatment and support for people with MS.

Its activities derive from a mission comprising five main objectives:

- Encourage MS research through recognised organisations
- Exchange and disseminate information relating to MS
- Promote collaborative programmes amongst national MS societies in Europe
- Facilitate interaction between institutions of the European Union, the Council of Europe and other organisations
- Propose new measures to advance the rights of people with MS and ensure their participation in society

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Opening Address to MS Conference

John C. Golding, EMSP President

Vilam agra la presència amb nosaltres dels Reialtaçonsaanyor del Consell Social de la Generalitat de Catalunya: Mr. Josep Lluis Cleres i Gonzàles.

I would also like to welcome all the speakers that will bring life to our workshops. That is to say CEOs and key staff volunteers of MS societies in Europe, representatives of MSF, people with MS and their caregivers, Young persons with MS, neurologists, representatives of RIMS, ECTRIMS, MS nurses, industry representatives and anyone else attending us.

In our workshops:
- We will try to bring you closer to current EMSP projects and to a promising pilot project in Scotland on MS and employment.
- In parallel, the YPAW will hear their own discussions about sexuality and pregnancy.
- We will learn about: the impact of female hormones on MS. About the progress in re-myelination research and about the stigmata of the whopping spectacles on offer in this beautiful city.

We have had a meeting of medical experts and the annual Council meeting yesterday and we are now ready to move by holding the Annual Conference and Youth Congress.

The EMSP is a platform for exchange of MS related information and examples of good practice. There are various channels for this task – our traditional Spring Conference is one of the most effective and important ones.

I would like to say a few words as to what you can expect to be addressed and discussed today and tomorrow.

As always in our Spring Conference: A leading expert will present an update on new MS treatments in the pipeline (Prof. Alan Thompson).

We’ll learn about:
- The impact of female hormones on MS
- About the progress in re-myelination research
- About carisma in management of MS symptoms and

To open this 2012 Annual Congress, I want first to congratulate the EMSP on its starting work in the area of MS, which I believe has brought benefits to all the national MS Societies represented in this room and to the 600,000 people living with MS across Europe.

As you know, Spain as a whole and its individual regions have had a long, hard struggle to achieve a welfare state. For many decades, the right to achieve was a right to have the little and they often looked for guidance from the MS societies who are close to the community and know the challenges.

Governments also need to take measures to break down the stigma that persists. In this regard, we also look for guidance from the MS societies who are close to the community and know the challenges.

In parallel, the YPAW will hear their own discussions about sexuality and pregnancy.

We will hear about national political developments in healthcare and social care since 2003, the year of the EU Parliament’s Resolution on MS.

And finally, we’ll try to inspire you by some examples of good practice in patient empowerment, taken both from national and from European level.

It is my sincere wish that you will find the programme interesting and rewarding and that it also allows you to meet and renew old friendships and also make new friends and contacts at the same time.

I will now like to give the floor to Councillor Josep Lluís Cleres i Gonzàles from The Generalitat of Catalonia.

To achieve this, governments have the responsibility to create an accessible society; this implies philosophies and practical action in areas such as universal access and eliminating barriers to employment, social activity and independent living. It also means looking at all diseases from a societal perspective, not just from the angle of health and disability.

I would like to say a few words about the importance of socialising and building networks, whether of friends or colleagues.

To achieve this, governments have the responsibility to create an accessible society; this implies philosophies and practical action in areas such as universal access and eliminating barriers to employment, social activity and independent living. It also means looking at all diseases from a societal perspective, not just from the angle of health and disability.

Given the current economic crisis in Spain, we are in a time in which it is particularly difficult to move forward in advancing in these areas. But we see an event like this as an occasion to learn from others and, hopefully, to advance more quickly and to lower cost based on their experiences. With this in mind, I wish you a very successful and engaging Congress.
Emerging Therapies and Multiple Sclerosis
Prof. Alan J. Thompson, University College London

Twenty years after the first effective medication for MS, interferon-β was approved by the US Food and Drug Administration, we can see encouraging milestones in the development of more therapeutic options. Just five years later, four agents were available that reduced relapse rates. Between 2004 and 2006, a second-line agent was licensed for more aggressive MS, withdrawing because of serious side effects and subsequently reintroduced. In 2010, we entered a new era of therapy, with the release of the first oral agent. Yet the unmet needs are very challenging in terms of ensuring access to disease-modifying drugs world-wide and in developing strategies to suppress inflammation and to protect and repair the central nervous system. There is also great need in symptomatic treatment and in prevention of MS.

The pipeline of therapies under development reflects that research in MS therapies continues, in three areas: regulating the immune system; reflecting that research in MS therapies continues the central nervous system, there is also great need in symptomatic treatment and in prevention of MS.

The greatest interest is on Fingolimod (marketed as Gilenya), which works by “sweeping up” the lymphocytes that attack the CNS. Two large clinical trials have shown positive results. In the TRANSFORMS study, Fingolimod was tested against interferon β-1a, similar results were seen in the FREEDOMS trial, which compared Fingolimod with placebo. As a result of these trials, Fingolimod was approved for two groups:

- Patients with high disease activity despite treatment with a beta-interferon.
- Patients with ≥2 relapses in one year or ≥1 Gd-enhancing lesion or a significant increase in T2 lesion load.

The studies revealed the need to monitor three areas of potential adverse effects: cardiovascular effects, a higher degree of respiratory infections and the development of malignancies (though no specific association has been verified).

Fumaric acid (Fumurate or BG00012) appears to dampen inflammation while also protecting against the neuronal death and damage to myelin.

The unmet need is massive

Disease-modifying therapies
- Neuroprotective strategies: Neuroprotective drugs aim to seal the blood-brain barrier; and protecting the CNS from demyelination or restoring the damage done by the disease.
- Neurorestorative strategies: New monoclonal antibody therapies now either available or in Phase III clinical trials include Alemtuzumab, Ocrelizumab and Daclizumab, all of which focus primarily on reducing the risk of attacks in RR-MS.
- Disease modification: The aim is to seal the blood-brain barrier, and protecting the CNS from demyelination or restoring the damage done by the disease.

The story of Natalizumab is well known: the drug was developed to seal the blood-brain barrier, making it impossible for leukocytes to enter the central nervous system (CNS) and attack tissue. Clinical trials against placebo over two years, Natalizumab showed an 81% reduction in the annual relapse rate and a 64% reduction in the risk of disability progression. But controversy arose from evidence that treatment increased the risk of developing progressive multifocal leukoencephalopathy (PML). Further investigation saw the risk for PML increase from 1:1000 to 2.3:1000, but also provided better understanding of the risk factors involved, which include:
- The time period over which a PwMS is treated with Natalizumab.
in the CNS. The therapy has shown positive results in two Phase III trials, one against interferon beta-1a, one against glatiramer acetate. Teriflunomide is a potent oral immunomodulator that regulates T-cell function while preserving vital salvage pathways. A placebo-controlled Phase III trial (TEMSO) with two dose groups showed that Teriflunomide reduced the annual relapse rate by 31% for both doses. The higher dose also significantly reduced by 30% time to disability progression. The drug was well tolerated, had a favorable safety profile and is now licensed in the USA.

Alemtuzumab (Lemtrada) targets CD52 receptors on lymphocytes and monocytes. It has been shown to be effective in early MS, delivering better results in terms of relapse reduction than interferon beta-1a. Some 78% of patients receiving Alemtuzumab remained relapse-free for two years (against 59% for interferon beta-1a); this reflects a 55% reduction in relapse rate. However, its impact on slowing disability was less significant and the therapy is known to have adverse effects including prolonged T-cell defects, stem cell depletion and autoimmunity Thyroid dysfunction (23%).

Ocrelizumab targets CD20-positive B lymphocytes. At two dose levels (150 mg and 300 mg), the SELECT trial showed substantial reductions in relapse rates (54% and 50%, respectively) and in reduced disability progression (57% and 43%). Several of these studies reflect an important development in how clinical trials for MS are carried out. Previously, all clinical trials involved therapy or no therapy (placebo), which placed half of the trial population at greater risk for relapses and progression of MS. Increasingly, trials include three groups: those on the trial therapy, those taking placebo and those continuing their current therapy. This makes it possible to measure the effect of the trial therapy not only against no therapy, but also against therapies already proven. The approach facilitates an evaluation of the added value of the new therapy.

Overall, these advances show promising results for two Phase III trials, one against interferon beta-1a, one against glatiramer acetate. Teriflunomide likely reduced the annual relapse rate by 31% for both doses. The higher dose also significantly reduced by 30% time to disability progression. The drug was well tolerated, had a favorable safety profile and is now licensed in the USA.

**Pathological Differences between RRMS and Progressive MS (PPMS, PPRM)**

RRMS

- Focal demyelinating lesions
- RRMS
- RPMS
- SPMS
- MS, blood-brain barrier injury

MS, diffuse axonal injury in NAWM

Inflammation in the CNS

- Extensive cortical
- Diffuse inflammation
- Compartmentalized demyelination
- Axonal injury in NAWM

Teriflunomide reduced the annual relapse rate by 31% for both doses. The higher dose also significantly reduced by 30% time to disability progression. The drug was well tolerated, had a favorable safety profile and is now licensed in the USA.

**Clinical Outcome Measures and Trial Design**

- **MESEMS trial,** now underway, has a robust sample size (~160 subjects) and 10 international centres participating for a two-year period. It is expected to provide valuable data on the safety and efficacy of MSCT.

**Important research is also examining neuroplasticity – i.e. the ability of the CNS to repair itself or to find new ways to perform functions despite CNS damage.**

The urgent need for therapies for progressive MS has prompted the establishment of the International Progressive MS Collaborative. A Consensus paper entitled “Progressive Multiple Sclerosis: Setting a Research Agenda” has been published in October's MSJ.
Gender Differences in Multiple Sclerosis

Mar Tintoré, PhD, MS Centre of Catalonia (Cemcat), Neuroimmunological Unit, Vall d’Hebron University Hospital

The predominance of MS in women over men – a ratio of approximately 3:1 for women in their 40s – is a result of complex interactions among female reproductive hormones and autoimmunity. This gender link is further evidenced in the fact that in pre-adolescent MS, the ratio tends to be 1:1 and in statistics showing that women in the relapsing-remitting stage tend to have a “more active” form of MS (characterised by more relapses). Although the causes are less clear, men appear more likely to advance to the secondary progressive stage or to be diagnosed with primary progressive MS.

Studies of women with MS before, during, and after pregnancy further confirm this hormonal link. During pregnancy, Th1 cytokine levels decrease while Th2 cytokines increase. With half of the raw material of a fetus coming from the father, the mother’s body recognizes the growing child as a “foreign invader”. To support its development, the mother’s body suppresses the immune system mechanisms that might otherwise reject the invasion. This immune suppression can have a protective effect for the mother, but during pregnancy, women with MS (Kasliwal and Gold, Nat. Rev. Neurol., 2012), experience less immune mechanisms that might otherwise reject the invasion. The hormonal changes that accompany birth of a child are often seen as the opposite effect: as levels of Th1 increase and Th2 fall down again, the risk of a post-natal relapse rises. These findings are important for women with MS: they demonstrate that past beliefs (“pregnancy may be dangerous for the baby”, “a woman with MS cannot cope with a mother’s duties”, “your MS will worsen”, “your disease can be passed on to the baby”) about pregnancy and MS were not based on evidence. They also help to answer questions that all women with MS ask when considering whether to have a family.

Will I have a normal baby? YES. There is no evidence of MS having negative effects (such as malformations or infant death) on the health of offspring (Mueller et al., Am. J. Obstet. Gynecol., 2002), nor are any changes noted for age of walking or talking, or other developmental stages. In the first year (Patti et al., J. Neurol., 2008), there is no increased risk of low birth weight (Dalt et al., Neurology, 2005), except if the fetus is exposed to interferon β in the early stages of development (Skovby et al., Nat. Rev. Neurol., 2005). Will my child have MS? The risk is slightly increased. In the general population, the incidence of MS is about 0.2%. In cases where the mother or father is affected, the incidence rises to 3% to 5%. For dizygotic (fraternal) twins, the risk is quite high (2% to 3%, for monogzygotic (identical) twins, the risk increases substantially to 20% to 26%. What if I get pregnant while I am on DMD treatment? Most neurologists will advise women with MS to plan their pregnancies according to their own wishes, but taking into account the severity of their disease. All will recommend stopping treatment before trying to conceive. For DMDs, the treatment should be stopped approximately one month prior, for Natalizumab and Fingolimod, it is recommended to discontinue these therapies at least four weeks prior to conception. A first study showed a small increased risk of spontaneous abortion, but no increase in the risk of congenital abnormalities (Skovby et al., Nat. Rev. Neurol., 2005); however, other studies have suggested that the rate of pregnancy cases for women exposed to interferon beta matches the rate in the general population.

Sex-related factors in multiple sclerosis susceptibility and progression

Rhonda R. Voskuhl and Stefan M. Gold

Table 1: Effect of sex-related differences on MS

<table>
<thead>
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<th>MS incidence (male)</th>
<th>MS activity (male)</th>
<th>MS progression (male)</th>
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<tbody>
<tr>
<td>Category A: Women more than men</td>
<td>Category B: Women more than men</td>
<td>Category C: Women more than men</td>
</tr>
</tbody>
</table>

- Category A: No risk for the fetus
- Category B: No risk for the fetus observed in animal studies. No controlled studies exist in pregnant women with interferons, Mitoxantrone and Natalizumab.
- Category C: Animal studies have shown abnormalities that did not result in spontaneous abortion. The risk of miscarriage is quite high.
- Category D: Evidence of infertility and abortions in studies or data during post-marketing.

No risk for the MS therapy during its earliest stages of development. A first study showed a small increased risk of spontaneous abortion, but no increase in the risk of congenital abnormalities (Skovby et al., Nat. Rev. Neurol., 2005); however, other studies have suggested that the rate of pregnancy cases for women exposed to interferon beta matches the rate in the general population.
that of the general population (Sandberg-Engl J Med, 2002). In another study of 88 Spanish women, covering both planned and unplanned pregnancies and reflecting exposure or non-exposure to DMDs, 75% of pregnancies advanced to full term while 25% were lost (Ol de la Hera, et al., Multiple Sclerosis, 2007). For full-term pregnancies, no malformations or neo- natal complications were reported (Pragossi et al., CNS Drugs, 2010) and the rate of Caesarean births matched the general population (Amato et al., Neurol, 2010). One study shows some risk of increased relapses connected with the use of assisted reproduction techniques, but the findings need to be further investigated and confirmed (Haufler et al., European Neurology, 2009). Similar findings were true for exposure to Gattamin® acetate (Saltmiren et al., J Neurol, 2010) and to Natalizumab (Hawige et al., MS Journal, 2011), although the data for Natalizumab-exposures are very preliminary.

**Will MS cause complications during pregnancy?**

**NO.** There is no evidence of increased complications during pregnancy in relation to the population at large (Mueller et al., Am J Obstet Gynecol, 2002). One study shows some risk of increased relapses connected with the use of assisted reproduction techniques, but the findings need to be further investigated and confirmed (Haufler et al., European Neurology, 2009). Similar findings were true for exposure to Gattamin® acetate (Saltmiren et al., J Neurol, 2010) and to Natalizumab (Hawige et al., MS Journal, 2011), although the data for Natalizumab-exposures are very preliminary.

**Will MS cause complications during pregnancy?**

**NO.** There is no evidence of increased complications during pregnancy. The PRIMS study group showed that relapse rates declined during pregnancy against the year prior to pregnancy; during the third trimester, the rate fell by as much as 70% (Conteúdo et al., N Engl J Med, 1998; Vukusic et al., Brain, 2004). This appears to be related to lower levels of Th1 and increased levels of Th2. If a relapse occurs during pregnancy, physicians are better prepared to treat, selecting the appropriate therapy typically with methylprednisolone in relation to the severity of the attack.

**Will I develop new symptoms during pregnancy?**

**POSSIBLY.** Some women experience an aggravation of existing symptoms or notice new symptoms, particularly in the areas of urinary problems, fatigue, sensory symptoms and gut abnormalities. Today, physicians are better able to predict who is at risk of post-partum relapse, which appears to be linked to three factors: a) the number of relapses in previous years; b) the number of relapses during pregnancy; and c) the degree of disability at the onset of pregnancy (Vukusic et al., Brain, 2004). If an attack occurs post-partum or during breastfeeding, the decision to treat or not should be taken together with the doctor. If treatment is to be pursued, the patient should stop breastfeeding.

Trials are ongoing to assess the possibility of pre- venting post-partum attacks through the use of steroids, intravenous immunoglobulin (IVIG), estro- gens or DMDs.

**Will my MS worsen following delivery of my child?**

**NO.** Studies indicate that deterioration post-partum and two years following is not beyond what is expected in the course of MS in relation to the type and stage at which the pregnancy occurs (Vukusic et al., Brain, 2004).

**How soon should I restart treatment?**

**IT DEPENDS.** Generally, restarting treatment is related to the severity of MS. It is important to note that women who restart treatment must discontinue breastfeeding.

Trials are ongoing to assess the possibility of pre- venting post-partum attacks through the use of steroids, intravenous immunoglobulin (IVIG), estro- gens or DMDs.
Myelin is a white membrane (80% lipid and 20% protein) that forms an insulating sheath around nerve fibres. It is crucial to the protection of axons in the central nervous system (CNS) and necessary to the rapid transmission of electrical impulses from one neuron to another. When demyelination occurs, the “stiff” of missing myelin causes the nerve to misfire — or not to fire at all. In MS, the loss of messaging between axons leads to clinical symptoms and the loss of axons (due to the loss of the myelin protection) leads to increased disability. The symptoms depend on the location of the demyelination.

Remyelination studies
Historically, it was believed that damage to the myelin sheath could not be repaired. Over the past 50 years, research has confirmed that remyelination does occur naturally, which ultimately prompted investigation into how it can be stimulated. In 1981 Bunge and others reported that remyelination occurs spontaneously, along with recovery of the impulses that had been lost. This was seen in the spinal cord of an adult cat. In 1965 Pieter and Gregoria found evidence of the first remyelination by observing myelin sheaths around nerve fibres. In 1981 K.J. Smith and W.I. McDonald found that remyelination could restore rapid conduction of electrical impulses.

From 2000–2008 — The groups of B. Blake (in MS tissue) confirmed that myelin protects axons from degeneration. Therefore, remyelination leads to protection against disability.

What does remyelination occur?
Once the possibility of remyelination was confirmed, the logical question was to ask: How does it occur? Further research shows that three types of cells are involved, each acting in different areas of the body. Each shows different potential to promote remyelination, in terms of both rate and zone.

Progenitor cells are a sub-set of cells that are not fully formed and, like stem cells, have the ability to differentiate into diverse adult cells. The most important difference is that stem cells can replicate indefinitely, whereas progenitor cells can divide only a limited number of times. Progenitor cells are now considered as the main contributors to remyelination in the adult CNS.

Why does remyelination fail in MS?
Seeing that this possibility for remyelination exists, we want to understand why it fails in MS. For this, we must first understand the different steps of the remyelination process. At present, all of this knowledge derives from experimental studies, both in vivo and in vitro. The main steps of the repair process are: 1) recruitment of oligodendrocyte precursor cells to the demyelinated plaques; 2) wrapping the new myelin sheaths around the denuded axons. In general, two main approaches for therapy have arisen from recent research: 1) finding ways to inhibit activity that blocks naturally occurring remyelination; and 2) transplanting cells (stem cells) that can develop into myelin cells in the area surrounding the lesion.

Inhibitors: various research groups are trying to develop compounds that promote remyelination. One of the most interesting and advanced is associated with Lingo-1, a natural protein in the brain and spinal cord that inhibits oligodendrocyte maturation and prevents remyelination in the spinal cord, but not in other areas of the CNS.
therefore prevents remyelination. Researchers are trying to develop compounds that inhibit production of Lingo-1. Some of these have been shown to be effective in experimental models. Phase 2 trials will begin soon, but it will be some time before this therapy is proven and available to patients.

Transplantation: efforts to transplant stem cells have also been tried using cells from bone marrow, from the peripheral nervous system, and from other sources. Five aspects of this line of research are of note:

- Hematopoietic stem cells (HSC) therapy leads to profound immunosuppression, but makes no contribution to repair (remyelination).
- Therapy using stromal cells also acts by modulating the immune system, however without demonstrated repair function.
- Schwann cells can be transplanted to stimulate remyelination, but they do not migrate within the CNS, so their effect is limited in regional scope.
- Neural stem cells also have an immune-modulatory role and might participate to repair indirectly (bystander effect) by favouring endogenous remyelination. However, their accessibility might be a concern.
- Stem cells from other sources:
  - Olfactory ensheathing cells (OECs) are found in the lining of the nose. Although they do not form myelin in normal conditions, when transplanted to the area of a demyelinated lesion, they are able to remyelinate.
  - Boundary cap (BC) cells are located at the interface between the central and peripheral nervous systems during development. Early studies show that BC cells are highly mobile and have a strong potential for stimulating remyelination.

At which stage of MS is remyelination effective?
As demyelination is an ongoing process in MS, it is valid to examine when treatment aimed at remyelination would be most effective. This is still an open question. In concluding, I wish to say a few words about the need to have hope as research advances in various areas of MS therapy – and yet be cognisant of the need for scientific proof that therapies are effective. Even if we are some years away from having a therapy to offer from the current work in endogenous remyelination, recent progress targeting inhibitors of remyelination is very encouraging. The same is true of stem cell therapy, which is still in quite early stages of investigation. It is important for people with MS to understand that much more academic investigation is needed in this area. Stem cell clinics are currently selling something other than effective treatment; they are offering only hope and illusion. They say that they cure everything, but they are doing it for money, not for science.
Cannabis in the Management of MS Symptoms

Patrick Vermersch, University of Lille Nord de France

Spasticity, like all MS symptoms, occurs as a result of myelin and nerve fibre degradation. It ranks seventh of the top 10 symptoms of MS; 82% of patients report experiencing spasticity, among which 54% say the symptom is moderate to severe. It is one of the most disabling symptoms, and one of the greatest unmet needs in symptomatic treatment. At present, spasticity progresses despite available treatments in its impacts, and many patients judge the current treatments as unsatisfactory. Apart from the associated legal issues, use of street cannabis raises other concerns. It lacks THC purity and contains high levels of tetrahydrocannabinol (THC; the psychoactive cannabinoid) and low levels of cannabidiol (CBD; the anti-psychotic cannabinoid). Moreover, it is known that smoking cannabis increases the risk of lung cancer, heart disease, etc., and that the substance has variable pharmacokinetics that cause very high THC peaks, which lead to psychoactivity and other adverse effects (Chong et al. Mult Scler 2008; 14: 838-45; Aldington et al. Eur Resp J 2008; 31: 280-86; Pioter et al. J Pain Res 2012; 5: 90-4).

These concerns prompted the development of cannabis-based pharmaceuticals. A key aim was to produce a standardised medicinal product based upon the main active constituents of Cannabis sativa: tetrahydrocannabinol (THC) and cannabidiol (CBD). Under controlled conditions, the substance can be formulated to ensure purity and stability. As an alternative to smoking, the therapy was developed to be administered through an oromucosal spray (Sativex) that provides a satisfactory pharmacokinetic effect while avoiding the high plasma levels and risks associated with smoking. This approach allows the benefit of the synergistic interaction between THC and CBD, with reduced psycho-active and enhanced cannabinoid-mediated clinical effects. Locking particularly at the drug Sativex, it is prepared from two chemovars of Cannabis sativa to ensure standardisation and quality. The two active ingredients, which are absorbed and appear in the plasma within 15 minutes, have complementary effects (see table). THCPs and CBDs have high levels of cannabidiol (CBD). These two cannabinoids account for about 70% of the composition of Sativex; the remaining 30% comprises minor cannabinoids, terpenoids, sterols and triglycerides.

Endocannabinoids are “Retrograde” Neuromodulators. (i.e. they are released from post-synaptic neurons and act at cannabinoid CB1 receptors on pre-synaptic axon terminals. THCs link to both CB1 and CB2 receptors, showing greater activity at CB2, subtypes (which may account for its psychoactivity). CBD has lower affinity for both receptors and is an antagonist at the CB2 receptor. Thus, CBD may act synergistically with THC to antagonize psychoactive and sedative effects while enhancing cannabinoid-mediated clinical effects. The two active ingredients, which are absorbed and appear in the plasma within 15 minutes, have complimentary effects (see table).

Maximum plasma THC levels with Sativex and Street Cannabis (smoked)

<table>
<thead>
<tr>
<th>THC</th>
<th>CBD</th>
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<tbody>
<tr>
<td>Appetite stimulant</td>
<td>Anti-psychotic</td>
</tr>
<tr>
<td>Analgesic</td>
<td>Anti-convulsant</td>
</tr>
<tr>
<td>Anti-anxiety</td>
<td>Antidepressant</td>
</tr>
<tr>
<td>Anti-spastic</td>
<td>Anti-convulsant</td>
</tr>
<tr>
<td>Anti-pain</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Anti-nausea</td>
<td>Antipsychotic</td>
</tr>
</tbody>
</table>

Cannabis (Cannabis sativa) has a long history of use as both a medicine and a recreational drug. Medicinally, street cannabis has been used for its anti-spastic, muscle relaxant and pain relief effects. In a UK survey of persons using cannabis medically (mosty smokers) between 1998 and 2002, almost 75% indicated that it was better or somewhat better than their previous treatment for MS or various pain states (Wane et al. Int J Clin Pract 2005;59: 291-95).

Apart from the associated legal issues, use of street cannabis raises other concerns. It lacks THC purity and contains high levels of tetrahydrocannabinol (THC; the psychoactive cannabinoid) and low levels of cannabidiol (CBD; the anti-psychotic cannabinoid). Moreover, it is also known that smoking cannabis increases the risk of lung cancer, heart disease, etc., and that the substance has variable pharmacokinetics that cause very high THC peaks, which lead to psychoactivity and other adverse effects (Chong et al. Mult Scler 2008; 12: 646-51; Wiae et al. Mult Scler 2009; 12: 639-84; Aldington et al. Eur Resp J 2008; 31: 280-86; Pioter et al. J Pain Res 2012; 5: 90-4).

Patients experience somewhat different degrees of effect, which highlights the importance of tailoring close amounts. The cannabinoids are quickly absorbed into body fat, but plasma concentrations following oral/nasal spraying are lower than those after inhalation because absorption is slower and redistribution into fat is rapid. The falling off of the effect happens in two phases; the initial effect falls off within about four hours and the substance is fully metabolised by the liver within 24 to 36 hours.

A third clinical trial expanded to include 572 patients in the United Kingdom and Romania, included 180 patients and assessed (as the primary outcome) the change in severity of spasticity using the Numerical Rating Scale. Secondary outcomes included the Ashworth scale, the motricity index, daily mean spasm scores and the patient’s global impression of change (Collin C et al. Eur J Neurol 2007; 14: 290-96). NRS scores were shown to be reduced by about 50%, with patients reporting an improvement of ≥30% from a baseline.

A second, smaller clinical trial had 337 participants assessed patients across Europe and included additional secondary outcome measures such as the timed 10-m walk, the Barthel ADL index, the Cana’s global impression of change, quality of life, and safety and tolerability. Again using the NRS, patients improved by ≥30% from baseline and also scored improvements on other symptoms: fatigue (51%), spasm (79%), bladder (73%), tremor (81%), pain (76%) and sleep (81%).

A subsequent long-term, follow-up study assessed patients who remained in the study for at least one year: symptom scores remained significantly lower with Sativex than baseline values. For example: spasticity was scored at 69.5 (0 weeks), 34.2 (10 weeks) and 31.8 (62 weeks). Of 23 patients who interrupted treatment for 20 weeks, 20% needed to resume Sativex before the end of 14 days due to re-emergence of marked symptoms. During the interruption period, seven patients reported adverse MS symptoms were much worse, 10 said that they were no worse, 5 the same and 3 reported an improvement in symptoms.

It is important to examine the adverse effects (AEs) of Sativex. During the first four weeks of exposure, the most common effects were dizziness (14% to 32%) and fatigue (12% to 25%); both were usually reported as mild to moderate and resolved quickly. When the recommended gradual “up titration” schedule was introduced, the incidence of AEs declined. Overall, the rate of withdrawal from the trials due to AEs was low. Importantly, Sativex does not exhibit the side-effects typically associated with recreational cannabis use (Wade et al. Mult Scler 2004; 10: 434-41; Wade et al. Mult Scler 2006; 12: 830-46; Collin et al. Eur J Neurol 2007; 14:290-96; Collin et al. Mult Scler 2007; 13: 571-29; Ambler et al. Mult Scler 2009; 15: 528). Results from controlled RCTs provide conclusive evidence of the short- and long-term efficacy of Sativex in MS-related spasticity, with half of patients clearly receiving benefit from this add-on treatment.

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A third trial expanded to include 572 patients in a two-phase study, with results again showing a ≥30% improvement. The measure of quality of life improvement were significant in this study; higher scores on the Barthel scale of activities of daily living; patients, caregivers and physicians noted higher global impressions of change, less sleep disruption; lower spasm frequency; and higher quality of life scores (Ambler et al. Mult Scler 2006; 15: 528; Montalbán & Wright Mult Scler 2009; 15: 527).

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Results from controlled RCTs provide conclusive evidence of the short- and long-term efficacy of Sativex in MS-related spasticity, with half of patients clearly receiving benefit from this add-on treatment.
Before mid-2011, health care was almost free for everyone in Portugal, with costs reduced by more than one month by the National Health Service (NHS) network. Hospitals and health centres provided services for people seeking treatment, regardless of their income or the health situation.

Due to the economic crisis, the newly-elected government took strong steps towards making drastic cuts in state expenditure in all areas. This has affected the health budget and, accordingly, the treatment of MS.

The NHS is has been given targets to reduce the share of health budget within gross national product (GDP) by 1.25% in 2012 and a further 1% in 2013. Over the period 2010-13, this equates to a 40% reduction in costs within the NHS itself. In 2012 alone, the health budget has been cut by EUR 800 million. Cuts are already evident on the weekly trip fall to the patient’s family, with the time and cost associated with the weekly trips falling to the patient’s family, with the time and cost associated with the weekly trips falling to the patient’s family.

From the results, the MS Society has noted some substantial changes, even though the fundamental mechanism of prices being settled by the Ministry of Economy and Regulatory Authorities remains unchanged.

The guideline that hospital pharmacies should deliver only one week of treatment per patient rather than one month of DMD therapy aims, in part, to avoid the lost of drugs that occurs when patients abandon the treatment. Under the new guideline, only one week is lost in such cases. But the guideline is very disadvantageous for people who live far away from hospitals; time and cost associated with the weekly trip fall to the patient’s family, neither on the government’s budget. Several fundamental problems are evident in the new model. With no national guidelines in place, decision making takes place locally and is inconsistent, often based only on price considerations. Difficulties in accessing MRA have a negative impact on diagnosis. Limitations in therapeutic options have effectively transformed the important role of the physician making the best decision for each patient to the hospital’s administrative authorities; neither physician decisions nor patient needs are adequately respected. Ultimately, reduced access to treatment increases the risk of more rapid disease progression for patients.
Empowerment Case for Poland
Luiza Wieczyńska, Deputy CEO, MS Society of Poland (PSTR)

SincE EMSP launched the MS Barometer in 2008, Poland has consistently been placed among the lowest-ranking countries in Europe. In 2011, Poland achieved a score of just 87 points out of a possible 225 – precisely 140 points below the first-placed Germany. But such comparisons are only one aspect of the MS Barometer; the other benefit of the tool is that it facilitates measurement of year-to-year progress within a given country. Unfortunately, even on this scale Poland has seen very little change: in 2009, Poland scored 70.

Access to the latest MS therapies is among the areas in which Poland attains a low score (72/70, placed sixth from the bottom). But somewhat surprisingly, Poland ranks 14th from the top in terms of empowerment of PwMS and has seen substantial progress in the past two years – rising from a score of 8 in 2009 (of a possible 35) to 118 in 2011. The key achievement is that PwMS are now represented in the MS Parliamentary Group. This consultation group comprises 13 Members of Parliament from diverse political backgrounds but united by a common interest: improving the situation of PwMS. Since it was established in 2011, the Group has met six times (organised by the PSTR) and has written numerous letters and undertaken various interpellations such as supporting PSTR initiative to change the rules restricting the therapy access.

Intense lobbying efforts of the PSTR, including the hosting with EMSP (in 2011) of a High-Level Roundtable, have also been empowering for the Society and for PwMS. Last year, the limitation on access to DMDs was extended from 3 years to 5 years, and an age restriction for those over 50 was eliminated. These advances still fall short of reflecting the recommendation of the European Code of Good Practice in MS, which states that treatment should be continued as long as benefit is evident. Such hard-won progress in the right direction is cause for celebration, but one must not overlook the reality that each PwMS in Poland has to face not only the disease, but a restrictive policy environment.

For this reason, the Medical Advisory Board of the PSTR undertook (in 2005) to develop a National Therapy Plan (NTP), which closely follow the Code of Good Practice and includes a detailed budget (updated annually). The Plan is multidisciplinary and emphasises the importance of multiple tasks in the course of treatment: disease-modifying therapy, rehabilitation, symptomatic treatment, the establishment of a national registry, etc. It aims to provide a comprehensive and professional system of care for PwMS. In 2012, the PSTR will update the content of Plan to reflect new treatments that have become available.

The Plan aims to see 500 new PwMS gaining access to DMDs each year, and to ensure that all those being treated receive an MRI annually to assess disease progression. Importantly, the Plan also calls for the opportunity for PwMS to change drugs during treatment if they find that one is not as effective as hoped or causes intolerable side-effects. Finally, the Plan calls for workshops and trainings for neurologists, nurses, rehabilitation experts and other MS specialists.

Overall results

Country

Luxembourg

Netherlands

Switzerland

Lithuania

Germany

Denmark

Austria

UK
A “Starting Point” for Living with MS
Kent Andersson, Treasurer of Neurologiskt Handikappades Riksförening (NHR), the Swedish Association of Neurologically Disabled

avstamp: The name selected for an educational programme for newly diagnosed PwMS, carries a strong sense of forward momentum: it translates as “starting point”, “kick-off” or “take-off”. The programme was launched by the Swedish Association for Persons with Neurological Disabilities (NHR) in response to a survey (2004) showing that many PwMS felt poorly informed about their diagnosis.

The avstamp programme aims to provide accurate information and give PwMS an opportunity to meet fellow patients and others who are newly diagnosed. NHR works closely with the Neurology Clinic, particularly MS nurses who play the critical role of identifying and inviting PwMS to attend avstamp events.

The programme is delivered over four evening sessions, covering four aspects of living with MS with relevant experts giving presentations and leading the discussion:

- What does my life look like after getting my diagnosis?
- Psychological aspects and society’s responsibility.
- Living with MS in daily life: Physiatrist + Occupational Therapist
- 4th evening: A separate lecture for family and friends.

The final evening is an important opportunity to explore how MS affects family life. NHR finds that most PwMS bring at least three family members to this evening, confirming that the disease touches everyone.

NHR feels programmes like avstamp should be a priority: many newly diagnosed patients feel that early treatment focuses solely on getting access to the right drugs. avstamp provides an opportunity to explore other topics important to coping with the reality that one has a life-changing disease.

avstamp is offered regularly in 15 centres across Sweden. However, NHR recognises that not everyone can attend in person. Thus, in 2012, the Association launched an online version of the programme that anyone can access. This specifically encourages those who wish to establish personal contact with other PwMS to share learning and experiences.

NHR was established in 1957 as an MS Society. Today, it represents a broader range of neurological disabilities and has approximately 13,000 members of which 60% are PwMS. NHR offers services through 98 local branches in Sweden.

National political developments in health and social care since 2003 in Serbia
Irena Đujić Bašuroski, MD, PhD, Ass. Prof., Neurology, University of Belgrade

Serbia (including Kosovo) has population of 7.1 million people, which is 12 times the death rate (13.85/1,000 people) exceeds the birth rate (9.15/1,000) and the fertility rate for women is 1.4. The median age is currently 41.3 years; average life expectancy is 71.49 for men and 77.34 for women. Health expenditure accounts for 9.0% of GDP and the physician ratio is 2.03/1,100 people.

The national health system offers three levels of care: primary, secondary and tertiary – and on a principle of universal access, with expenses and all costs being covered by the national health institution. However, to obtain care, an individual must obtain a health card, which requires registration of the place of residence. A key challenge in this regard is that a very low portion of the Roma population is registered and many do not have legal status. It should be noted, however, that in cases of emergency, health services are provided to all in need.

In 2001, the Serbian healthcare system was functioning poorly on several levels. Overall, the system was very fragmented, which had a negative influence on the continuity of care. Services were managed by low efficiency and uneven quality, and by a lack of motivation to engage in health promotion and disease prevention. Attempts to include health consumers in primary health care (PHC) policy decisions were taken with a non-systematic approach and therefore of limited value.

In 2002, the government launched a reform of the healthcare system based on a report entitled ‘Health Care Policy: The Vision of Health Care System Development’. A 2006 analysis noted the development of a network of PHC institutions (comprising 158 PHC-centres) and stated that 36% of all doctors work in PHC, with general practitioners making up 17% of the total number of doctors.

The reform has achieved several important aims, including a better definition of healthcare institutions according to the healthcare levels. At the individual level, the chosen doctor concept includes the doctor’s role in establishing a patient-physician relationship, the definition of the medical consultation, and the development of the role of the general practitioner.

The new model of care includes the principles of coordination of care, prevention of disease, and systematic care. A key challenge in this regard is the need to increase the number of primary care doctors and to improve their level of education and training.

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Health-related strategies of the Republic of Serbia

The 2010 Serbia Strategy: from a clear vision and advancing to legislation enacted at national and local levels...and institutions. This effort was based on 130 health care institutions and decentralised social care services (instead of social care institutions). It also sought to transform residential social care services to community-based social care services. Serbia also received funding from the Canadian International Development Agency (CIDA) to support the PHC system development.

Building on these achievements, Serbia is now focused on the implementation of a Strategy and Action Plan of the Health Care System Reform until 2015, which is based on numerous documents published in the past 10 years, as well as legislation enacted at national and local levels. The reforms aim to improve health care for all, start to improve infrastructure and advancing to a strategy and action plan. The 2010 Serbia Progress Report, prepared by the European Agency for Reconstruction project for Improving Preventive Health Services in Serbia, was introduced, which also facilitated the process of establishing a new strategic support as the sub-law on community service standards, which was also adopted. In response, the Serbian government has prepared a new strategic document, Serbia 2020, which sets two main goals:• to define the framework for the Republic’s socio-economic development up to 2020,• to continue reforms in the sphere of health care, both in terms of finance and management of the system, with the goal of improving the quality of health care for all citizens, especially children and vulnerable groups. Serbia acknowledges the high value of cooperation with NGOs and aid organisations in working toward these goals. Complementary to the health care reform, Serbia has also made substantial progress in five areas of social care: developing a strategy for social care; introducing new social welfare law and sub-laws; establishing a social protection chamber; deinstitutionalising children with disabilities; and promoting cross-sectoral cooperation, including international and intergovernmental at such as the sub-law on community service standards, which was also adopted through consultations with stakeholders and is aimed to be adopted by the end of 2012.

The Social Protection Chamber establishes ethical regulations and oversees licensing for social care services. In undertaking health and social reform in parallel, and establishing clear priorities in both areas, Serbia has taken an important step towards a more holistic approach to the overall well-being of its citizens – particularly those in vulnerable groups. Historically, the poor and disabled in Serbia have faced discrimination and unemployment, and experienced limited access to education and financial assistance.

It goes without saying that people with MS fit into this group of vulnerable persons. The MS Centre at the Clinic of Neurology, Clinical Centre of Serbia (Belgrade) estimates that there are 6,000 PMwMS in the country. The main problem is limited access to disease-modifying drugs (MDMs), which are currently not available in Serbia. At present, only about 550 PMwMS in Serbia are treated with MDMs (260 with interferon-beta 1b, 260 with IFN-beta 1a, and 23 with glatiramer acetate). Due to very limited financial resources, the National Health Insurance (NHI) Fund restricts access to these drugs: a special expert committee for economic development for the NHI fund, is an ongoing need to work with MS Societies to increase pressures on the NHI fund to help and raise public awareness. A specific issue exists in Serbia regarding the IFN-...
Recent Developments in Patient Involvement in the EMA

Lisa Murphy, co-chair of the PCWP and a patient representative of EURORDIS and Christoph Thalheim, EMSP representative at PCWP

During the period 2007 to 2010, patient involvement in activities of the European Medicines Agency expanded substantially – from just 70 patients participating to more than 300 interventions. Patients became active in Scientific Advisory Group (SAG) meetings, safety communications, consultations for both the Committee for Medicinal Products for Human Use (CHMP) and the Scientific Advice Working Party (SAWP), and in workshops and conferences. A particularly important development has been the recognition of patients as “experts” in high-level meetings. As noted below, 2010 marked a real turning point in the level of patient involvement.

Patients now serve the EMA in many roles. Some act as full members of the Management Board (EMD), the Committee for Orphan Medicinal Products (COMP), the Paediatric Committee (PDCO), the Committee for Advanced Therapies (CAT) or the Patients and Consumers Working Party (PCWP). Others play a role as Observers of the Pharmacovigilance Working Party (PRWP) and, from July 2012, the Pharmacovigilance Risk Assessment Committee (PRAC).

Their involvement has led to invaluable contributions to the review of product information, including EPAR summaries, patient leaflets and safety information (DSAs). Their advice and collaboration in the CHMP supports input on product assessment and the preparation of guidelines.

Their experience is also valuable to experts in the areas of scientific advice/protocol. Involvement in other initiatives – such as the European Network for the Safety Assessment of Medicines and Pharmaceuticals (ENCePP), Eudravigilance (a data-processing network and management system for reporting and evaluating suspected adverse reactions), and the European Network of Paediatric Research at the European Medicines Agency (ENPEMA) – is equally important.

EMSP is pleased to be involved in EMA activities through the Working Party with Patients and Consumers’ Organisations (PCWP), which focuses on improving transparency, informing patients on medicines, pharmacovigilance and interaction with scientific committees.

As those who live with disease, patients provide patient perspectives that add value to risk-benefit assessments and risk minimization strategies. They are particularly important in the development of the new Paediatric Committee for Orphan Medicinal Products ( COMP), the Paediatric Committee (PDCO), the Committee for Advanced Therapies (CAT) or the Patients and Consumers Working Party (PCWP), and in workshops and conferences. A particularly important development has been the recognition of patients as “experts” in high-level meetings. As noted below, 2010 marked a real turning point in the level of patient involvement.

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Following the MS-NEED Survey (carried out in 2011), EMSP has been leading a pan-European initiative to enhance recognition of the role of MS nurses and to unify their knowledge and expertise through certified training. A key aspect of this project is the online delivery of training, which broadens access and is well-tailored to individuals who are already working as professional nurses. Increasingly, both health professionals and MS patients acknowledge the key role MS nurses can play within a multi-disciplinary team (MDT). In fact, bringing MS nurses directly into the relationship between neurologists and patients establishes mechanisms and links to enhance care, and thus outcomes. The MS-NEED survey found that MS nurses play a central role in the long-term management of PwMS and often provide significant support, which has a positive effect on both coping and compliance. The presence of an MS nurse significantly reduces the neurologist’s workload and is also cost-effective for health systems.

The MS-NEED Survey identified three key findings and set relevant recommendations:

<table>
<thead>
<tr>
<th>Finding</th>
<th>Recommendation</th>
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<tbody>
<tr>
<td>Role of MS nurses is evolving and expanding</td>
<td>Recognise MS nursing as a specialty across Europe • Need for shared MS nursing educational and support structures/resources across Europe in range of settings that include web technology &amp; social media • Ensure there is a structured, formalised and improved partnership working within current European forums and international organisations</td>
</tr>
<tr>
<td>Best practice sharing can enhance MS nurses role within the MDT</td>
<td>• Need for a stepwise professional development structure against an agreed European definition for MS nursing</td>
</tr>
<tr>
<td>Tools and education are needed</td>
<td></td>
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The pan-European unification of MS nurses will increase quality of care for PwMS and their families, and will also directly address the European Commission’s Green Paper: Modernising the Professional Qualifications Directive (2005/36/EC) - focused on preparing for mutual recognition of a national degree (such as an MS nurse exam) across all member states. The MS Nursing Project is a collaborative effort of EMSP, Rehabilitation in MS (RIMS) and the International Organisation of MS Nurses (IOMSN).
Despite advances in some areas in some countries, overall the MS Barometer results of 2011 show a downward trend against 2009. What is unchanged is that huge discrepancies exist among countries, which means that a large number of PwMS in Europe do not have the same opportunities for treatment, care and independent living.

In the autumn and winter of 2011/12, a team of five photojournalists travelled to 12 countries to capture how health and social policy influences – for better or worse – the daily lives of PwMS. The team worked closely with the MS societies, and was thus able to identify individuals whose situation reflects the positive and negative aspects of each country.

At the two extremes, the team saw first-hand the profoundly negative impact of inadequate policy in Belarus and the ways in which policies that support independent living empower PwMS in Iceland and Germany.

The MS Society of Belarus estimates that 300 PwMS live in the capital city of Minsk. None have access to DMDs or to rehabilitation, and many reach advanced stages of disability at very young ages. Moreover, Soviet-style apartments and poor infrastructure are substantial barriers to mobility. The Society believes that about 430 of these people are rarely able to leave their apartments, and live in a state of poverty because of low disability pensions.

By contrast, MS-félag Íslands (MS Society of Iceland) is able – through government support – to operate a day centre that can accommodate 40 PwMS each day. Aside from providing services ranging from rehabilitation to psychotherapy, the Centre has facilities for recreational activities. In many ways, it serves as a community Centre for PwMS living in Reykjavik. The city is equally remarkable for its accessibility legislation, which makes it easy for PwMS to travel on electric scooters or in wheelchairs.

Germany is equally noteworthy for its high level of access to therapies, and for the exceptional rehabilitation programmes offered at the Quellenhof Centre. A large number of PwMS (primarily those with additional private health insurance) are eligible to spend 1 to 3 weeks at the Centre each year, where a multidisciplinary team develops a programme that focuses on the patient’s current needs and personal goals.

Jesús Mora López-Almodovar told workshop attendees that he chose to participate in the UNDER PRESSURE project because he felt MS remains poorly understood by both the general public and by policy makers. Allowing everyone to see into his daily life is a way to send important messages that may help to improve the situation for fellow patients in Spain and across the European Union.

The photographers confirmed Jesus’ perception: all admitted that before becoming involved in this project, they had very little exposure to MS. Now, they have friends with MS who are quite likely to have very different quality of life, simply because of the country they live in. The photographers are united in their desire to use this project to bring media attention to the situation of PwMS across Europe.

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Belarus, Estonia, France, Germany, Greece, Iceland, Ireland, Italy, Poland, Spain, Romania and the United Kingdom.
Introduction

Emma Rogan, Ireland, Chairwoman of the 2012 Youth Conference.

Carrying on the successful gatherings in 2010 and 2011, the EMSP Youth Congress continues to be an opportunity for representatives from all over Europe to share experiences, discuss different issues and to create plans for positively changing the experiences of Young People with Multiple Sclerosis (YPwMS) in their home countries and in Europe as a whole.

Barcelona was the location for the third Youth Congress held on May 19th 2012. It was an opportunity to reflect on the work done since the last two meetings of YPwMS and look to the future work of the group. There were eighteen attendees from thirteen countries: Belgium, Czech Republic, Denmark, Estonia, France, Greece, Ireland, Italy, Lithuania, Netherlands, Norway, Romania and Spain. Gender composition of the group was seventeen women and one man. With such a diverse gathering in terms of nationalities, it was a fantastic opportunity to share different cultural experiences particularly related to the main topics.

Chosen over the last twelve months through online collaboration and following on from previous years, the topics of Sexuality and Pregnancy when living with MS were the issues for discussion in 2012.

YPwMS consider these issues very important for their lives now and in the future. Discussing what are sometimes considered private, taboo topics in a clear and openhearted fashion was a way to open up the dialogue for MS societies across Europe. These are topics fundamentally important for all young people, straight, lesbian, gay, with or without MS and they are issues that affect us all on a deep, emotional level.

During the previous twelve months Julie Deléglise, EU Affairs and Membership Officer at EMSP, liaised with a group of people from the Youth Congress. Following questionnaires, teleconference interviews and careful collaboration, a video about these issues was produced. Sexuality and Pregnancy with MS is a short film showing the experiences of a young woman as she deals with MS in her daily life as an individual, as a worker, as a partner and as a mother.

The film had a profound effect on many people at the Youth Congress - it was true to people’s experiences as well as humorous - and proved to be an excellent way to open up the discussion of topics that, due to cultural and social taboos, many thought had been ignored and not treated with enough consideration.

This video is available at www.emsp.org
Before starting to talk about sexuality we saw the movie “Sexuality, Pregnancy and MS”. I invite you to watch it: www.emsp.org. We discovered the movie is a fantastic tool to start discussions about sexuality, pregnancy and MS. We all like to know about these subjects and enjoy sex life, but to talk about sex...that is another story! It was a significant film for many of the participants, causing a profound effect because the characters portrayed many of the issues faced in the daily reality of life as a YPwMS.

As sexuality is a difficult subject to talk about, we tried to get answers to the following questions:

- Which sexual changes (physical and psychological) do young people with MS have to face?
- How to cope with these changes?
- What are the strategies to better communicate with your partner, lover, friends, doctors, healthcare professionals, sexologists?
- To recover and enhance body image, self-worth and sexual confidence?
- To have a fulfilling sexual life (sex toys, dildos, lubricants, body mapping...)?
- Do national MS societies provide support and/or counselling to young people with MS regarding intimacy and sexuality?

A lot of YPwMS seem to have problems with fatigue, loss of sensitivity/sensability, cramps and tension. Even the thoughts of having cramps during sex cause difficulties and are a common problem.

Talking to your partner is a major issue. As problems are common when we have sex, they are not the same issues every time and might not be an issue at other times. MS can be a problem in a relationship, but do not make MS the most important thing in the relationship. We have discovered that partners of YPwMS are often forgotten. Partners may think they are the problem, when actually it is other issues that are causing their partner with MS the difficulties. Without communication, it is very easy for our partners to misunderstand what the issues are and to know that they are not the cause of them.

Often, it is the lack of communication about the issues (bladder, cramps, poor body image) that is the cause of sexual issues.

Of course we need to focus on a good life together. A quality weekend for the couple once a month for instance. Children are out of the house, spending a lovely time at their grandparents, and creating a romantic atmosphere.

Being positive, having fun and enjoying the pleasures of sex is very important and is something that needs to be planned. Having lunch in a nice restaurant, walking in a park, swimming in the sea, go to the cinema and watch a nice movie, buy flowers...things that make the other person feel loved and special is a vital part of ensuring the sexual aspects of a relationship are given opportunities to flourish.

There are cultural as well as personal issues that might prevent people from talking about their sex lives to their neurologists, doctors, or other healthcare professionals. Also, because positive sexual health is often not discussed by health professionals, YPwMS get the impression that it is not important. If healthcare professionals were willing to discuss the issues of sexuality and pregnancy, YPwMS would be more open and have the opportunity to fully discuss the impact MS has on our sex lives.

Our national MS societies provide some information about sexuality in brochures, small newsletter columns, on Facebook and their own websites. It was suggested that future workshops about sexuality should be planned with other topics included.

Love yourself and love each other. When sex happens it happens, but it is all about a good time together. Look for ways to do the things you enjoy most with the people you like the most!
Don’t be ashamed, talk openly to your partner about your feelings regarding having children.

“It’s a paradox. How does one balance living in the now with preparing responsibly for the future? The key to this dilemma lies in the distinction between ‘worrying about the future,’ and ‘preparing for the future.’ The two concepts are not at all the same.”

Jonathan Lockwood Huie

To kick off this workshop, the 18 participants were asked whether they have children or not:

- There were three YiPwMS with children;
- One YiPwMS was five months pregnant;
- There was one man present in the group and his wife was pregnant;
- Some YiPwMS had a dilemma about whether to have children;
- Other YiPwMS were sure they definitely wanted to have children.

Knowing this, I could finally begin to start the discussion. The following points were discussed:

- Due to treatment, do persons with MS face infertility?
- Is pregnancy causing new symptoms?
- Is pregnancy worsening the condition? To what extent?
- Do pregnant women with MS have to stop their treatment during their pregnancy?
- By choosing to have children, do people with MS feel guilty? Safely? By choosing not to have children, do people with MS feel guilty? Safely? What are their concerns?
- Where does research stand with MS and heredity?
- Where does research stand with MS and heredity?
- Strategies to communicate with the partner, the relatives, friends, doctors?

Some of these questions were handled very easily. Others were more difficult. To discuss. We all have MS with personal experience of the condition. However, we are not doctors or professors. We cannot give exact information on some points; we can only clarify certain aspects by using our experience. A psychologist in the group shared her experience and advice regarding some points raised in the discussion.

The three mothers in our panel all shared their experiences. It was a big advantage to have these mothers among us, because a lot of us are still struggling with the dilemma of whether or not to have children.

They were clear: they did not face any new symptoms. During their pregnancy, they felt similar to how they were before they were diagnosed with MS. They recovered skin sensitivity, the tingling in their hands/feet/limbs had gone, fatigue levels improved as well as many other positive effects. They all were in good condition. According to the testimonies, pregnancy can have a significantly positive influence on the woman’s MS.

The group agreed that it is necessary to stop the treatment(s) during pregnancy. But, anecdotally, there was a known person with MS, who did not know she was pregnant until she gave birth to a healthy son! The baby boy was examined but there was no problem at all. Was this an exception? We suppose so. We still shared the same opinion that it is “advised” to stop treatment. Something else that we need to consider.

There was a discussion about being selfish or being guilty when choosing whether or not to have children. Someone in the group immediately shared her opinion, “When you try to get pregnant, it is not selfish at all to continue your treatment”. Everyone agreed. But then the discussion started again on “What if you don’t know yet if you’re pregnant?”

Some thought YiPwMS should stop their treatment a few months before they get pregnant due to the potential side-effects on the foetus. Following this, another point of discussion started. “What who can we count on during pregnancy and when the child is born?”

Someone came up with a brilliant idea for couples to plan quality time together. Asking relatives or friends to take care of the children during a weekend, so the person with MS can have some rest and the couple can have uninterrupted opportunity for their relationship.
We also referred to the realistic short film, shown at all the start of these workshops. It showed a few situations during and after pregnancy and gave some reasonable solutions – ways of helping, supporting the partner of the pregnant PwMS, the parents and close relatives, close friends. There are some services which you can count on after giving birth which offer help with the child and help you to manage your housekeeping. We do not know exactly where this research stands. What about the effects of treatment on the pregnancy? We all agreed that it must not be good. But a lot more research on this needs to be done. What about these children when they grow up? Will they get sick? Does it influence their health? So far, we did not hear a negative story on this issue. But we agreed that research certainly must be continued!

We also agreed about the focus on the use of hormones. They seem to have a positive effect on pregnant woman with MS.

We all agreed that the video on Sexuality, Pregnancy and MS will be a “must have” in every MS environment! Social workers, social nurses, the MS communities, the neurologists, everyone in the field MUST see this film and they must spread it via websites, Facebook, meetings, conferences and workshops.

Couples and family projects

The MS is a complex disease that affects not only the individual but also people who are around them, including their partners and limbs. In all aspects of everyday life, from the emotional to the practical, the family has long been the focus of projects run by the MS Society, which aims to provide valuable support and facilitate the experiences of those who live every day with MS. It was possible to collect and identify the main difficulties that families can encounter, with many of the initiatives designed to address their specific needs.

Women’s project

The Italian Experience

Silvia and Federica, Italy

Women’s project

EMSP | Annual Congress May 2012 | Barcelona

Women and MS. The Italian MS Society (AISM) has thought up a specific project focused on the implications and aspects that are typical for women, and paying special attention to what is like to be a woman with MS. The aim is to provide accurate tools for women with MS and create with them a direct channel for understanding and monitoring their needs. The project proposes various innovative ways to focus on all topics of interest to women with MS, and involving women, who may then take on active roles.

Launched in 2007, the project anticipates the organisation of seminars - for women only on this subject to promote the dissemination of accurate and up to date information, and foster dialogue and debate. These will be reinforced by the creation of an archive of videos online on topics chosen directly by women with MS and the publication of books on topics specific to women. This project will also encourage the sharing of experience – the telling of personal stories that can help understanding what it means for a woman to live with MS.

The Italian experience is wonderful, a big responsibility and every decision involves you. Not knowing what will happen in the future is a risk for all, not only for persons with MS.

The experience of parenting is wonderful, a big responsibility and every decision involves you. Not knowing what will happen in the future is a risk for all, not only for persons with MS.

The project includes several activities: information sessions, opportunities for socialising with MS and the sharing of expertise, training sessions, and publications. In particular, it is planned to organise annually:

- A 4-day stay at the Holiday House in the Sunflowers Lucignano during which families will have the opportunity to meet with professionals, such as neurologists, social workers, employment law experts, psychologists, and physical therapists to discuss major concerns and issues related to...
MS. The formal sessions are accompanied by information activities for relaxation and recreation for adults and children.

- Weekends for couples spent with a psychologist to examine the internal dynamics of the couple living with MS.
- Training meetings for organizing self-help groups to promote opportunities for sharing, exchange of experiences and information among peers.
- These activities are connected to the continued need to produce appropriate publications for the family, either downloadable from the website or found in the library.

Web Quiz

AISM has a new information tool: a series of Web quizzes on specific disease topics, to increase knowledge, recount the experiences of people with MS, dispel doubts and facilitate comparison. Web quizzes are useful for testing yourself, answering questions on everything about MS, reading in detail, writing reviews and if possible passing the quizzes. If you get the wrong answer, you can read the right answer, with a small explanation, below the questions.

Conclusion

Emma Rogan (Ireland)
Chairwoman of the 2012 Youth Conference

Multiple sclerosis affects not only the individual but also the partner, the lover, the family, the friends and all those who experience the repercussions of life with MS. Communication is one of the most valuable tools we have to create change. It is by being strong together, nurturing one another and being active participants in our lives that the needs and issues of life can be dealt with.

Using the personal experiences and the strategies developed, the EMSP Youth Congress wants to ensure that the topics of sexuality and pregnancy will be considered as important as other issues.

It is from the discussions of MS and sexuality and pregnancy in an open way that YPwMS will create a resource pack applicable to all European MS societies. The relationships formed during the first EMSP Youth Congress in 2010 continue to flourish and we all look forward to a better future for YPwMS in Europe.
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