EMSP

Annual Congress 2011

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emsp

european multiple sclerosis platform aisbl

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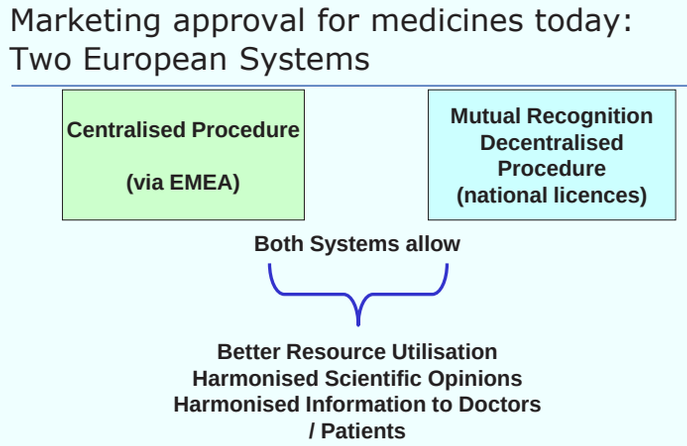


The Importance of Patient Input for the Work of the European Medicines Agency

Juan García Burgos, MD, Head of Public Information and Stakeholder Networking, UK

Role of the EMA

- Evaluation of Marketing Authorisation applications submitted by pharmaceutical companies, for certain types of products
- Coordination of pharmacovigilance at European level (supervision of the medicines on the market)
- Provision of scientific advice on the development of medicines
- Evaluation of applications for orphan designation in EU
- Evaluation of paediatric investigation plans (or waivers)
- Provision of good quality and independent information on medicines it evaluates to patients and health professionals

The European Medicines Agency (EMA), established in 1995, is a decentralised agency of the European Commission that provides European institutions and Member States with scientific recommendations of the quality, safety and efficacy of medicines (both human and veterinarian). One of EMA's main responsibilities is the evaluation of marketing authorisation applications submitted by pharmaceutical companies. The European Commission (EC), based on the Agency's recommendations, issues a marketing authorisation valid throughout the European Union. Evaluations are conducted on all innovative medicines including those for neurodegenerative conditions such as MS.

As part of the marketing authorisation, the EMA also provides a single source of product information, translated into all appropriate languages.

The EU is a single market for pharmaceuticals, representing approximately half a billion people. The company producing a medicine must acquire the Marketing Authorisation from the EC before it can start marketing the product. Even with EC approval, the product is then subject to national legislation of EU Member States, which have full control over general distribution, including advertising, pricing and reimbursement.

In order to thoroughly and accurately evaluate applications, the EMA partners with more than 40 national competent authorities, 4 000 EU experts, the EC and the European Parliament. It also has strong relations with non-EU regulatory authorities, international health organisations, industry, academia and the general public.
Patient involvement has always been important to the EMA and has developed over time. To

Selection criteria for involvement of patients' organisations

- Legitimacy
- Mission/objectives
- Activities
- Representativity
- Structure
- Accountability and consultation modalities
- Transparency

strengthen interactions with patients' organisations, the EMA Management Board has adopted a framework covering the scope of the interaction, the objectives to be achieved, the working methodology and tools for monitoring implementation, including performance indicators.

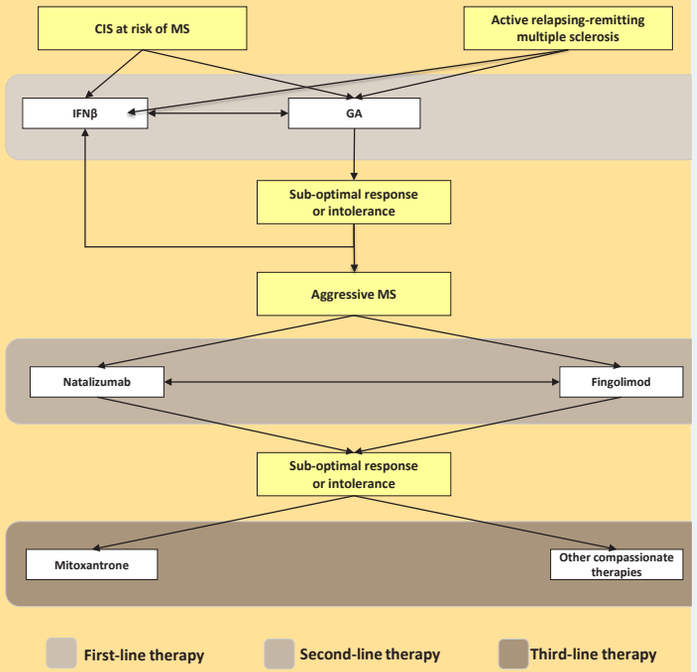
The framework formalised the EMA Patients and Consumers' Working Party (PCWP), which has two key aims: enhancing patient participation in EMA activities and providing better information to patients. This framework also defines the selection process for participating organisations, which is based on a permanent call for interest (initially launched in 2005) and continuous selection. The patients review product information, collaborate on the assessment of products and medicines, provide input in preparing guidelines, and regularly participate in workshops and conferences organised by the EMA.

The EMA views patient input as vital to the evaluation process. 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. Such involvement not only empowers patients and promotes their own health and safety; it also increases transparency and builds a reciprocal trust in the regulatory process.

Representatives from patients' organisations are now full members of the Management Board and of several of the Agency's Committees (the Paediatric Committee, the Committee for Advanced Therapies and the Committee for Orphan Medicinal Products.) To date, approximately 250 patients are active in the Agency's work every year. However, several challenges remain. Many patients' organisations lack the resources (both human and financial) to use this mechanism to its fullest potential. The EMA recognises the need to develop training to help patients understand the regulatory environment, and to more clearly define the patient's role in EMA activities and scientific committees. The EMA is very committed to pursuing practical work with patients; more feedback from people using the medicines will improve and strengthen operations, and support the ultimate goal of improving the lives of patients.

News on Disease-Modifying Therapies

Prof. Michel Clanet, CHU Toulouse, France and President of ECTRIMS



Any discussion of "what's new" in disease-modifying therapies for MS must include three elements: information on current treatment strategies; a look at future oral and non-oral treatments; and an examination of drug safety and risk.

Generally, as the flow chart shows (modified from Rio et al., 2011), the strategies for therapy depend, first of all, on the type of MS and then on how the individual patient responds to various options and how the disease progresses. This is known as an "escalating" approach.

Molecules being developed for future MS therapies act on multiple pathways and therapeutic targets. Some focus on the immune system, others on the blood-brain barrier (BBB), and a third group on the periphery or central nervous systems (CNS).

Oral therapy

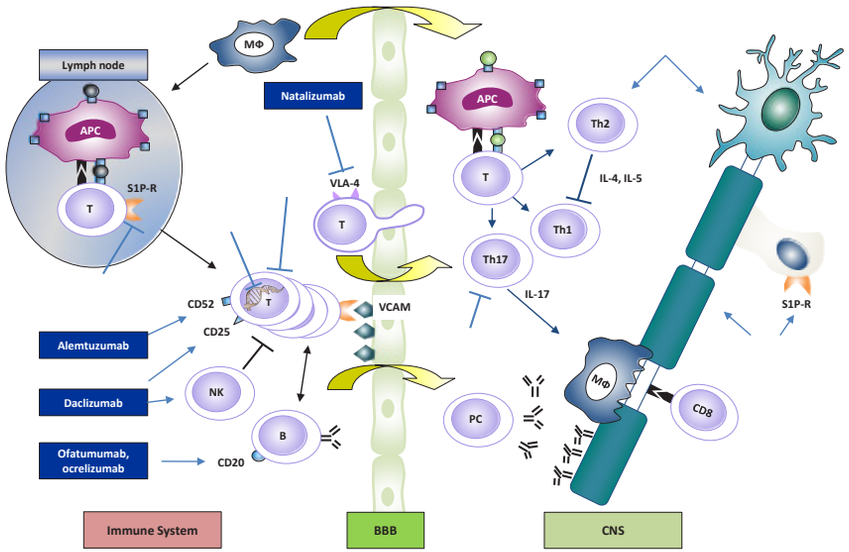
The recent development of oral therapies for MS is an important step toward simplying treatment from the patient's perspective. Several new drugs are either in development or now available in some countries.

Fingolimod is the only existing therapy that has effects on both the periphery and central nervous systems. It is shown effective for patients with relapsing-remitting MS (RRMS) for two groups of adult patients, including those with:

- High disease activity despite treatment with beta-interferon.
- Rapidly evolving severe RRMS, defined by two or more disabling relapses in one year, and with one or more Gadolinium (Gd+) enhancing lesions on brain MRI, or a significant increase in T2 lesion load as compared to a previous, recent MRI.

Two main trials showed that Fingolimod acts on the inflammatory activity associated with MS; it effectively decreases the number of relapses and reduces the severity of the patient's Expanded Disability Status Scale (EDSS). However, the trials completed to date aim to prove efficacy and some uncertainty remains about the safety of the molecule's biological profile. There is some evidence of cardio-vascular disorder, macular

Molecules in development for Multiple Sclerosis act on multiple pathways and therapeutic targets



APC, antigen presenting cell; BBB, blood/brain barrier; CNS, central nervous system; IFN, interferon; S1P-R, sphingosine 1-phosphate receptor; TNF, tumour necrosis factor
Image adapted from: Linker RA *et al. Trends Pharmacol Sci* 2008

edema, respiratory disorders, lymphophenia and liver dysfunction, as well as infections, neoplasms (tumors) and teratogenecity (causing birth defects). Considering these risks, patients using Fingolimod must be registered with a risk-management plan. All drugs with an uncertain safety profile are registered with accompanying strict recommendations of use and an enhanced pharmacovigilance programme.

Cladribine is an immune-suppressant that acts on a sub-category of lymphocytes with potential aggressivity against the central nervous system. In clinical trials, it showed efficacy in relation to reduction of relapse rate and EDSS. The relation between safety and efficacy, however, was not positive and the drug was not registered. In September 2010, the Committee for Medicinal Products for Human Use (CHMP) found an increased incidence of cancer among patients in the trial who were receiving the drug compared to the control group, and that the most appropriate dosage had not been established. As a result, the CHMP was of the opinion that the benefits of Cladribine did not outweight its risks, and refused marketing registration. In January 2011, a re-examination led to continued concerns about the drug's long-term safety.

Teriflunomide was tested in a randomised trial of 1 088 patients over two years; no severe adverse effects were reported and findings were released at the ECTRIMS meeting in 2010. This compound also shows efficacy on relapse rate and on EDSS; it is now in the process of registration and its safety profile seems to be quite interesting.

Laquinimod is an oral therapy that was tested against placebo in the Allegro study design using a two-year trial at 139 sites in 24 countries.

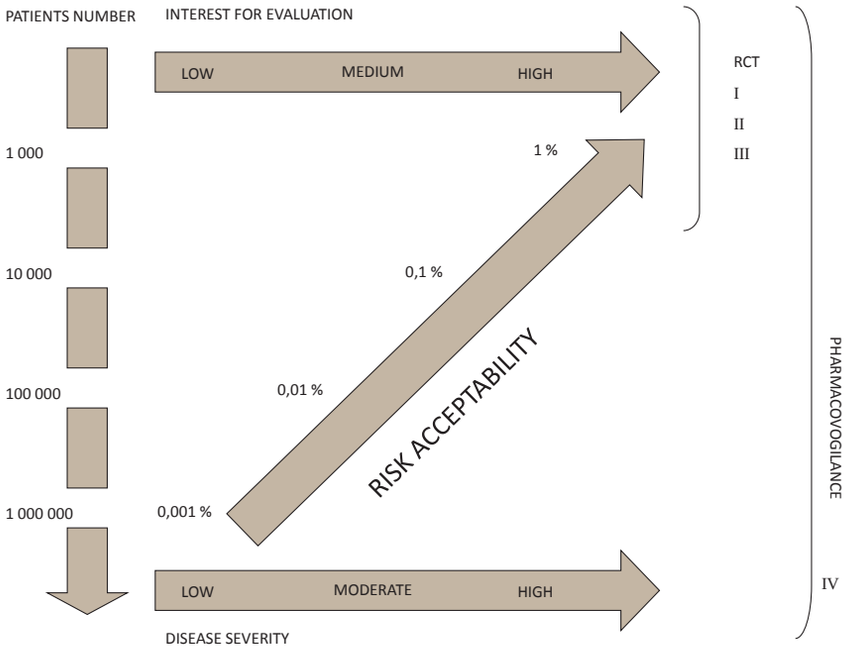
Using one daily dose (0.6 mg), it was shown to reduce relapse and Gd+ lesions (37%). It also had a positive effect on EDSS scores, evident in a 36% reduction in time sustained to disability progression. This study has not yet been published.

Fumarate (BG12) targets different aspects of the immune system first, and appears to also act on the nervous system. Early results show a decrease in activity of MS, with quite a good safety profile. Findings from the early trials are expected at the next ECTRIMS meeting (October 2012, Lyon).
In the next two years, we can expect to see various oral therapies with different levels of activity in different areas of the immune system. The risk-benefit profiles will vary, but the availability of oral therapies should improve overall treatment of patients.

Non-oral therapies

Natalizumab (Tysabri) is an infusion-based therapy (monthly) directed against adhesion molecules in the lymphocytes. In France, its use is tracked by a registry (TYSEDMUS), which shows a total of almost 3 900 patients. Results from the first 1000 patients treated show that the drug is efficient: there is a strong reduction of relapse rate and stabilisation of EDSS; EDSS improved in 46% of patients after one year, and in 48% after two years.

There is, however, a strong corresponding risk for the JC (John Cunningham) virus and to progressive multifocal leukoencephalopathy (PML), which should be stratified for each patient. If the patient has no previous contact with the virus, the risk seems to be low. It is now possible to test whether the patient is positive – i.e. has the antibodies needed to fight the virus. The risk is higher under other conditions. If, for example, the outcome of the antibody test is positive, the risk is further assessed in relation to prior use of immuno-suppressants. Initially, the risk increases with the number of infusions and the duration of treatment. After 36 infusions (3 years), the risk seems to stabilise but the confidence interval is large. At present, none of the data for stratification of risks for Natilizumab are certain at the scientific level.



Alemtuzumab is known to have strong effects on MS. In early trials, it was shown to be efficient on all patients, but results are only preliminary as the large Phase III trial is still in progress. The general expectation is that the drug will be shown to be effective but risk profile is very high. Its very strong immunosuppressant effects leave patients more susceptible to other auto-immune diseases.
This brings us to an important point about the intrinsic risks of immune-suppressants – in suppressing the immune response to MS, they also leave the individual more susceptible to other conditions such as:

- Malignant diseases, including infections related to EBV, HHV-8, H Papillomavirus, HBV, HCV, and Helicobacter.
- Lympho-proliferative diseases, Kaposi sarcoma, anogenital, liver and stomach cancers.
- Infections and immune dysregulations.
- Cardiovascular and metabolic risks.

When deciding whether to release new therapies to the market, authorities often take into account two factors: the severity of the disease and what these authorities consider to be an acceptable level of risk.

Factors in shared decision making

Increasingly, we recognise that this equation also plays out in individual treatment: the doctor and physician deciding together what they see as acceptable risk. Many patients at more advanced stages of MS are willing to accept higher risks of adverse effects if there is a chance that doing so will improve their condition. We also see that when such patients become stabilised, they often choose to continue the treatment to maintain this improved state, even though they know they are at greater risk of contracting PML.

Medical experts play an important role in this exchange: for the patient, they are the key source of objective and clear communication on treatment risks. In turn, medical experts need to be highly attuned to the attitudes of their patients. Some patients are likely to be risk-seeking; others will be more risk-averse. Understanding this risk perception on the part of the patient is vital to gaining – and maintaining – a patient's trust.

As noted, the current strategy for MS therapy follows an "escalation" path – that is, as the disease progresses, the therapy is adjusted accordingly. The development of oral treatments is certainly a positive aspect and we can now see that monoclonal antibodies are powerful agents for aggressive RR-MS, but the safety profiles of some new agents remain uncertain. For these reasons, medical experts and patients must focus – together – on optimising the process of shared decision making.

Aminopyridine-MOA

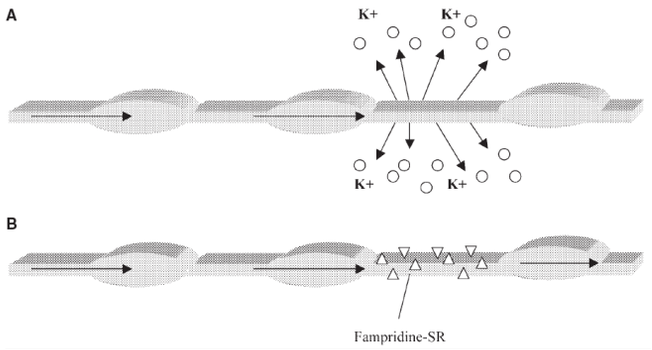


Figure 1. Downstream effects of sustained-release (SR) fampridine. A: In multiple sclerosis, demyelination of axons exposes voltage-gated potassium channels, diminishing formation of a normal action potential and limiting neuronal conduction. B: With fampridine-SR, exposed voltage-gated potassium channels are blocked, restoring neuronal conduction and action potential formation.

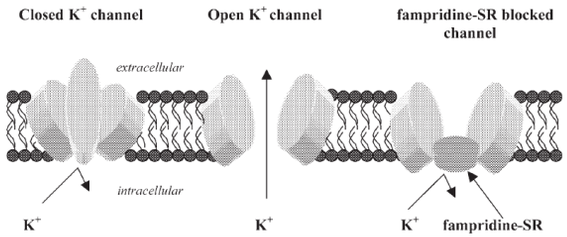


Figure 2. Mechanism of action of sustained-release (SR) fampridine.

New Treatments for Spasticity and Other Symptoms

Norbert Goebels, MD, Associate Professor, Department of Neurology, Heinrich-Heine-University, Düsseldorf, Germany

Treatment of MS typically follows one of two main approaches. Causal therapy involves immunomodulation and is considered an investment into the future, treating the underlying autoimmune disease. Symptomatic therapy, by contrast, focuses on providing "immediate" relief from specific symptoms of the disease. Loss of mobility and spasticity are two of the most common symptoms experienced by PwMS; fortunately, important new drug developments are proving effective in their treatment.

Loss of mobility

Loss of mobility ranks third among the ten most common MS symptoms. A UK study shows that 91% of patients are affected, and 79% rate the symptom's impact as ranging from moderate to severe. Fampridine is a 4AP compound that significantly increases action potentials of unmyelinated/demyelinated nerve fibres. In PwMS, demyelination of axons exposes voltage-gated potassium channels, diminishing formation of normal action potentials and limiting neuronal conduction. As a result, PwMS lose potassium through these exposed channels. Studies confirm that sustained-release (SR) fampridine blocks the channels, restoring neuronal conduction and action potential formation.

First impressive effects of aminopyridine were shown in the 1980s: a case study followed one patient with impaired eye movements (internuclear

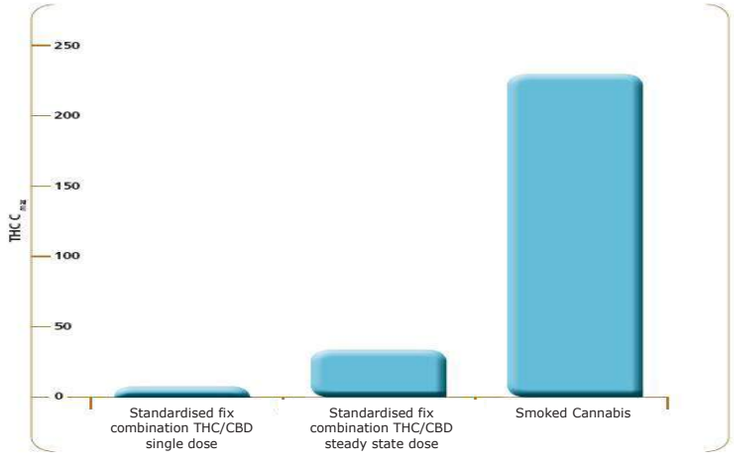
ophthalmoplegia) due to demyelinating brainstem lesions. Only 75 minutes after taking the aminopyridine medication, the patient's eye was fully mobile, but 220 minutes later the effect had entirely worn off. Even if the dose was increased, the pharmacokinetics remained the same. This rapid fall-off of positive results prevented a wider use of early AP therapies as a pharmaceutic agent in MS.

Pharmaceutical companies Biogen-Idec and Acorda solved this problem by developing extended release Dalfampridine, a similar compound that still modifies axonal function but is released over a sustained period, thereby prolonging the duration of action and decreasing side effects. Companies performed a trial measuring a timed 25-foot walking test among approximately 530 patients who took the drug twice daily, including a placebo group. The trial lasted nine weeks and, as expected, the placebo group showed no improvements. However, more than one-third of the treated patient population ("responders") experienced a 25% increase in walking speed, while non-responders showed no significant improvement. Nearly 40% of patients responded to the drug and showed a consistent increase in walking speed, with results being similar across all three forms of MS. In terms of side effects, seizures were observed with the initial non-SR drug, but were not evident with use of the SR version. Dalfampradine is licensed in the United States (as AMPYRA®) and annual treatment costs per patient are more than USD 12.000! A conditional marketing authorisation for Europe was granted in May 2011.

Spasticity

According to the same UK survey, 82% of patients experience spasticity, 54% of whom rate the impact of the symptom as moderate or severe. The seventh most common symptom of MS, it is also one of the most disabling. Like all MS symptoms, spasticity results from the degradation of myelin and nerve fibres. MS plaques inhibit the supra-spinal control of reflex activity and impair functional movement of muscles in the trunk and extremities. Progressive damage can result in the loss of inhibition and disruption of the stretch-reflex arc – a condition that exemplifies the

Maximum plasma THC levels with the standardised fix combination THC/CBD and Street Cannabis (smoked)



Guy & Stott In Parnham et al. (eds) Milestones in drug therapy: cannabinoids as therapeutics, 2005.

importance of being cognisant of what diagnosis really means:

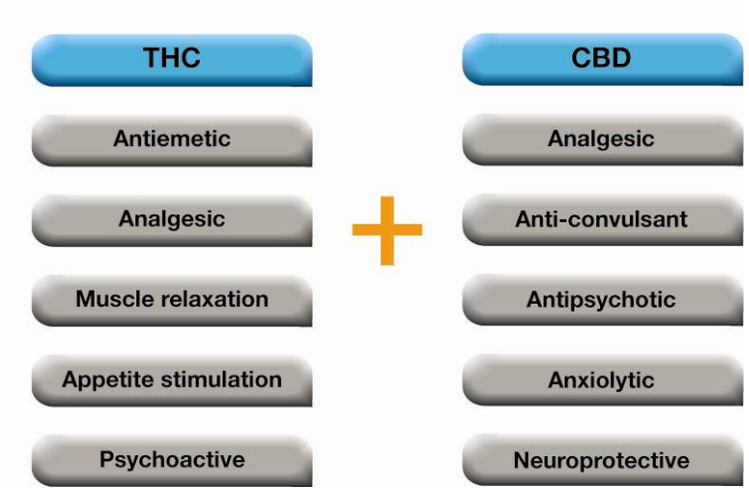
- A specialist may define the condition as "disordered sensorimotor control resulting from an upper motor neuron lesion, presenting as intermittent or sustained involuntary activation of muscles."
- A patient is more likely to describe the physical experience as "an unusual tightening of muscles that feels like leg stiffness, jumping of legs, a repetitive bouncing of the foot…".

However, existing treatment, which relaxes muscles, is not always the preferable solution: many patients would rather have a spastic leg than a "soft" leg that cannot carry their body weight. Slowly increasing dosage of oral anti-spasticity agents (z.B. Baclofen/Lioresal® or Tizanidin/ Sirdalud®) can help reduce general spasticity while Botulinumtoxin (Botox) can be used to treat focal spasticity. Other options include multimodal rehabilitation, physiotherapy and aerobics.

Cannabis has long been recognised as an off-label medication appreciated for its anti-spastic qualities, muscle relaxation and pain relieving effects. A UK survey of persons using cannabis medically between 1998 and 2002 showed that almost 75% considered it better than their previous treatment for MS or various pain states.

Use of street cannabis, however, raises legal issues and lack of standardisation carries risks: a recent sampling exercise reported very high levels of THC (Tetrahydrocannabinol, psychoactive cannabinoid) and low levels of CBD (Canabidiol, antipsychotic cannabinoid). Furthermore, cannabis is largely consumed via smoking, thereby increasing the risk of many diseases and causing a variable rate of pharmacokinetic activity, often leading to psychoactivity and other adverse effects.

THC and CBD: synergy (complementary effects)



Like the naturally occurring endocannabinoids in the brain, consumption of phytocannabinoids can influence the release of neurotransmitters involved in the regulation of appetite, pain sensation, mood and memory. To harness the therapeutic aspects of cannabis, researchers have been developing a product that balances THC, the psychoactive cannabinoid, with CBD, the receptor antagonist that blocks psychoactive effects.

The product is designed to be administered oromucosally (i.e. through a nasal spray), thus providing a satisfactory pharmaco-kinetic profile while avoiding the high plasma levels and risks associated with smoking. The spray – marketed as Sativex® – is formulated to ensure purity and stability, and to use the body's own cannabinoid system to regulate the action of neurotransmitters. With this spray, patients reported fewer incidents of the adverse effects associated with straight cannabis use; some dizziness and fatigue remained in a few cases, but these symptoms were quickly resolved. No consistent withdrawal syndrome has been observed, and there has been no evidence of drug misuse or abuse.
Sativex® is now being licensed as an "add-on" treatment for MS patients with moderate to severe spasticity who have experienced unsatisfactory results from other anti-spasticity medication.
At present, Sativex® has been approved for use the United Kingdom, Spain, Czech Republic, Canada and New Zealand; approval is expected soon in Germany, Denmark, Sweden, Italy and Austria.

Assistive Devices in Europe: What People with Disabilities Should Know

Gert Jan Gelderblom, PhD, Zuyd University, Board Member, Association for the Advancement of Assistive Technologies, Netherlands

The Association for the Advancement of Assistive Technology in Europe (AAATE) aims to stimulate the development of and access to assistive technology (AT) for the benefit of all people with disabilities. A member-driven organisation, AAATE is an interdisciplinary, pan-European and non-profit association founded in 1995. Membership is free and open to all individuals and institutions across Europe.

Wheelchairs, crutches and scooters are the most common forms of AT, but in its broadest sense, the subject covers 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. This definition embraces fields of interest that reflect a wider orientation on disability, technology and inclusion, such as accessibility of buildings and environments, and adaptation of the home. Increasingly, it stems from principles associated with eAccessibility, Ambient Assisted Living and Design for All.

The Association has found that funding for such activities is available from various sources across Europe – insurance plans, reimbursement schemes, etc. However, it is not always easy to access or equally available in all countries.

Like EMSP, the Association plays an advocacy role at the European level in the areas of policy and funding. The AAATE cannot directly influence either aspect, but can advise the European Commission on effective measures. In turn, the Commission can seek to harmonise different perspectives by establishing Directives for legislation. The Commission has shown itself to place high value on best practise. Yet ultimately, both of these areas fall under national policy: the Commission can establish directives and monitor activity; the Association can advocate and advise. But neither can direct policy implementation or influence funding distribution.

Both the Association and the Commission emphasise that accessibility is a human rights issue. The key objective of the AAATE is to enable disabled people – including people with MS – to

In order to advance assistive technologies, the AAATE focuses on innovation and invests in:

- technological research;
- developing, producing and distributing new products and services;
- improving understanding of how to match AT to individual users;
- increasing AT provision, including funding;
- training of professionals and end users;
- assessing outcomes of AT use.

enjoy their right to dignity, fulfil their capabilities, access equal treatment, live independently, and participate in society and the economy. The three operational objectives of the Disability Action Plan (DAP), established by the European Commission in 2003, provide a dynamic framework to collaboratively develop the EU disability strategy:

- Create anti-discrimination legislation and measures, thus providing access to individual rights and Employment Equality.
- Eliminate barriers in the environment that prevent disabled people from exercising their abilities and improve accessibility for all.
- Bring disability issues into mainstream Community policy discussion in order to facilitate the active inclusion of people with disabilities.

Many challenges still remain in developing and implementing accessibility policies and services. Translating “good intentions” into effective use of technology by people with disabilities in real-life situations is difficult, as is ensuring that products and services remain user-centered. Specific solutions based on specific needs are critical to empowering the end user. Proper training of staff and users is vital, and innovative research must be continuous. People with disabilities and their specialists also need (free) access to independent, professional advice in choosing solutions, which must remain affordable and sustainable. There is an urgent need to move from approaches and services based on traditional medical models towards efforts that are rooted in human rights.

Getting AT on the European agenda continues to be one of the Association’s main goals. To facilitate this, AAATE provides a range of services to members such as participation in conferences, workshops, seminars and special interest groups, subscription to the Technology and Disability journal and access to up-to-date information about education, employment, etc. through the quarterly newsletter. Members can also exchange experience and information through contact points in 20 European countries and a comprehensive website: *www.aaate.net*.

European Disability Strategy 2010-2020

A new framework for action

- empowerment of people with disabilities to fully enjoy their rights
- elimination of barriers

8 areas for action:

- Accessibility :Ensure accessibility to goods, services and assistive devices for people with disabilities.
- Participation
- Employment
- Education and training
- Social protection
- Health
- External action

Home Adjustments and Workplace Modifications

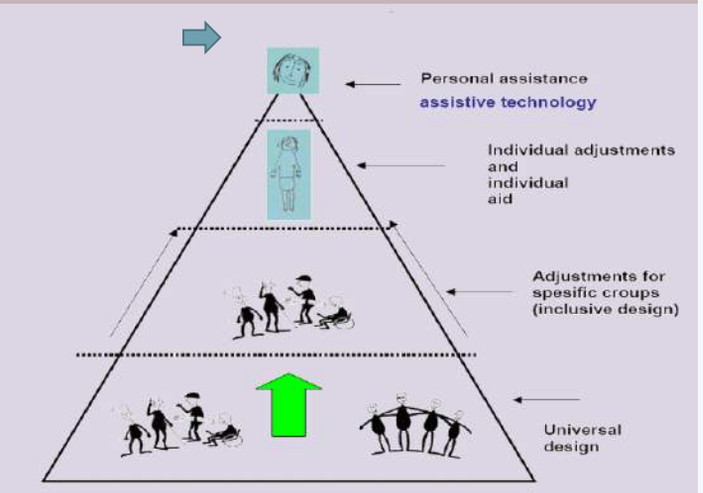
Marijke Duportail, Occupational Therapist and expert on home adjustments, National MS Centre Melsbroek, Belgium

For PwMS, a well-designed home or workplace can be an important factor in level of independence. Poorly designed environments can act as barriers to self-empowerment and reduce overall quality of life, for both the short and long terms.

The concept of "intelligent design" seeks to create a home or workplace that will allow all its inhabitants, despite age or ability, to live comfortably and well. An intelligent home is "wired" to enable complete control over all aspects of the home environment – from lighting and climate to music and appliances – from any location. But intelligent also means an adaptable design with a dynamic vision of how the needs of inhabitants will change over their lifetimes.

Studies show that people in wheelchairs do not have significantly different space requirements to carry out most daily activities. A person carrying their shopping, manoeuvring a broken arm, having a conversation with someone else or doing the laundry occupies approximately the same circumference of space as someone in a wheelchair, for example. These findings demonstrate that there is no real reason to apply different design approaches specifically for wheelchair users.

Universal design, also called Design for All, further develops this idea and refers more broadly to a design philosophy that can be applied to buildings, products and environments. It starts from a macro approach to design that is founded on the aim of increasing general, unanimous



The Accessibility triangle. The Norwegian Delta Centre

ease of use and then further refines design to reflect the needs of specific groups and, finally, of individuals. The goal of Design for All is to create spaces that are inherently accessible to both people with and without disabilities and devices that serve everyone's needs. Conceived by architect Ronald L. Mace, universal design should be "aesthetic, usable and accessible to the greatest extent possible by everyone, regardless of their age, ability or status in life".

At present, most existing and new housing – even in the wealthiest nations – lacks basic accessibility features unless the designated, immediate occupant currently has a disability. Design for All, which is gaining increased attention from the European Commission, encourages manufacturers and service providers to produce new technologies that are suitable for use by everyone. For people with disabilities, accessing and using many standard objects and spaces is a significant challenge. Accessibility refers to making these available for use, whereas usability considers the ease of use. A house following Universal Design principles will, for example, have no stairs, no ramps or thresholds in doorways, showers without stalls, an angled opening on washing machines, and appliances and counters placed so as everyone can access them with ease.

As evolution of MS is unpredictable, it is vital to incorporate preventative and long-term planning in the design of home and work environments, and to consider adequately the needs of caregivers and fellow employees.

While much of the work associated with these design concepts is carried out by architect and engineers, occupational therapists (OTs) can contribute to the process. As OTs are skilled in the assessment of living and working situations, and practiced in making recommendations to improve accessibility, they can become involved in both the adaptation of existing housing and the design of future housing.

Occupational therapists also often intervene in the workplace, considering two important aspects:

- *Time and energy management*, which focuses on rest-work periods, distribution of energy during the day, and ergonomical elements that can reduce fatigue.
- *Technical intervention*, which is more directed toward advising on ergonomic products, assistive devices and alterations of the physical workspace.

Their interventions often combine ***concept ergonomics***, which address the general design of workspaces and the tools used, and ***corrective ergonomics*** that aim to rectify the situation with personalised ergonomic appliances, such as magnifying computer software. Ergonimic principles for PwMS in the workplace should encourage dynamic movement and avoid prolonged static contractions. To accommodate for sitting at a desk for extended periods, PwMS should be shown how to maintain a correct posture and equipment should be placed at recommended heights and in easy-to-reach locations. The workplace should be well organised and equipped with appropriate adaptive devices. Design for All incorporates the notion that special features in buildings, products and environments should be integrated so that they are unnoticeable. Architects, designers and occupational therapists should take care not to confront any of the users – whether disabled or not – with an overwhelming number of devices. This issue is particularly important to PwMS, who are already confronted with an unpredictable disease that demands continuous adaptation to new life situations. Efforts to create new “norms” for products and living/working environments that are aesthetic and practical create a more comfortable and common lifestyle for everyone.

Medical Devices Don't Have to Make You Sick!

Emma Chappel, Urology Nurse, UK

The neuro-degeneration associated with MS is known to impair bladder control, which can have serious impacts on mobility and overall quality of life. Nerves travelling through the spinal cord play an important role in transmitting messages between the brain and the bladder to control the urinary system: when functioning normally, nerve receptors in the bladder signal that it is starting to fill up; in turn, the brain signals the sphincter muscles to release, thereby allowing the bladder to empty. When nerve damage occurs, transmission of these signals becomes interrupted, which can lead to incontinence (the lack of voluntary control over urination), retention (failure to eliminate urine from the bladder) or a combination of the two. Urinary tract infections (UTI), which result from residual urine in the bladder, are also a common and painful problem for PwMS.

PwMS can explore several solutions to this problem. Non-medical options include measures such as decreasing caffeine intake and performing pelvic floor exercises to strengthen the muscles used to control the bladder. Alternatively, PwMS may opt to take medication or to use catheters, including self-catherisation devices. Intermittent self-catheterisation (ISC) is the option most urology specialists recommend: it is the most effective solution for complete bladder emptying and it enables individuals to carry out their normal, daily activities with confidence.

Benefits of ISC

- Decrease the risk of UTI.
- Help reduce spasm which worsens if bladder is full or a UTI is present.
- Sleep better: ISC prior to bed will completely empty bladder and reduce the number of bathroom visits per night; helps prevent night-time leakage.
- Reduce worry and fatigue: visiting the toilet frequently is tiring.
- Alleviate baggage; no need to have a permanent catheter attached to bag.
- Improves quality of life and increase independence.
- Allows for sexual relationships.

Intermittent Self-Catheterisation (ISC): Up Close and Personal

Dan Cooper is 36 years old and lives in Southend, UK
He was diagnosed with relapsing remitting MS nearly six years ago and this is his personal testimony.

At first this illness was invisible to others. Apart from numbness and pins and needles in various extremities around my body, the only other symptom I had was a highly unpredictable bladder. Provided I could plan my day around toilet "pit stops", I felt I had this under control. As the illness progressed, however, I realised my control was gradually being compromised. My MS-specialised nurse agreed, and that's when she first suggested intermittent self-catheterisation.
Shortly after our discussion, a DVD arrived on my doorstep. It showed me how to self-catheterise. "Terrific," I told myself sarcastically after watching it. But still, I went ahead and contacted my continence nurse to try out a few different types of catheters.

A meeting was arranged with a continence nurse who very kindly agreed to come to my home and show me how to self-catheterise. After being given a demonstration, I was asked if I wanted to go to the toilet and have a go.

Unfortunately, this first attempt was a complete disaster! I was shaking so badly, I dropped the first two catheters on the floor and had to throw them both out; I managed to slide the third one about three inches inside my penis before dropping that one, too. When I called out to ask the nurse if she had any more, she offered to come in and help me. So in she came – complete with more catheters – and put on the rubber gloves. Now that made me really nervous!

Trying to control myself I thought, “Just close your eyes and think of something else – anything other than what’s happening!” Now that might sound like a good idea, but it was impossible for me not to look, so I watched as she slowly slid the catheter into my urethra. It was a shock to see it go in all that way before reaching my bladder, only it stopped just short of arriving at its destination.
I couldn’t believe that I had put myself through all that for nothing. From doing my own research, I knew the blockage could be due to a number of reasons – an enlarged prostate or constipation, but the most likely was that I was tense. I tried to cough, take a deep breath and everything else she suggested, but nothing worked. I aborted my attempts at ISC there and then. I thanked the nurse for trying to help me, and she went on her way. I was happy that I had tried, at least.

A year later, I was asked if I wanted to try a new disease-modifying treatment, and finally decided on Tysabri. My MS specialist nurse warned me that urinary tract infections were a common side effect, and that I would need to completely empty my bladder regularly.

This time, I was determined to self-catheterise, no matter what. If I couldn’t do it for myself, I had to think of my wife and kids. I prepared myself with alcohol. I wasn’t drunk, but I decided to tackle this task with my wife and the help of quite a few beers. It worked a treat. On the first attempt I drained off about 400ml of urine and for the first time in two or three years, my bladder felt empty. What an unbelievable feeling it was! It felt great, and I wanted to feel like that all the time.

I have been performing ISC for a couple of years now, and it has had a major impact on my ability to lead a more normal life. Now when I leave the house, I am far more confident knowing that my bladder has just been emptied and that – courtesy of my rucksack which contains a supply of catheters, wipes and disposable bags – I have the ways and means to empty it again, as and when necessary. My rucksack is also a little lighter to carry, as I no longer need to keep it stuffed with spare clothes in case of emergencies!

Stimulation triggered by a tilt sensor

New Assistive Devices for Footdrop and Intention Tremor

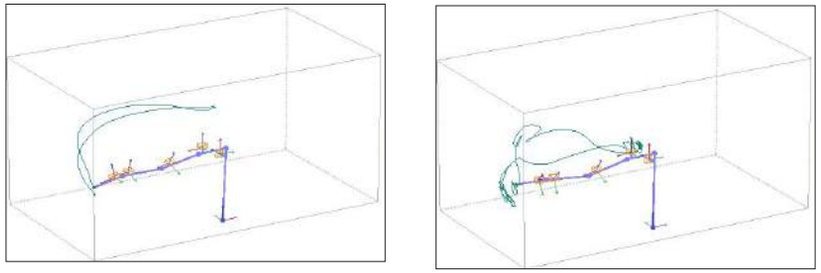
Angela Davies-Smith, Research Physiotherapist, BrAMS Centre, Bristol, UK

Assistive technologies being used and developed by the Bristol MS Research Unit (now based at the Bristol and Avon Multiple Sclerosis Centre, BrAMS) in Frenchay Hospital give PwMS more choice in coping with footdrop and intention tremor, two of the most inhibitive effects of MS. The Unit participated in two EU programmes that aimed to understand and quantify the full extent of these effects, and then to develop devices that reduced their impacts. Mobility is a major concern for PwMS: many are diagnosed when they are young, and the Unit recognises their desire to continue to lead active lives.

Footdrop refers to the inability to lift the foot during the swing phase of walking, which leads to trips and falls, and makes walking difficult and tiring. In MS, this is due to demyelinating plaques in the motor pathways of the spinal cord. Usually footdrop is unilateral but it can occur bilaterally and often becomes worse as the person becomes fatigued. Footdrop can, to some extent, be corrected by splinting or orthotics, but these solutions are often cumbersome and ineffective. Functional electrical stimulation (FES) for footdrop in MS was first developed in the 1960s and triggered by a pressure sensor in the heel. A relatively new device, WalkAide utilises a tilt sensor that triggers stimulation according to the position of the leg relative to vertical (see diagram) and is individually programmed according to a person's walking characteristics.

The WalkAide cuff, which is worn just below the knee, holds two stimulation electrodes against the skin: one over the nerve that sends messages

3D plot during a finger-to-nose test
(viewed from behind)



3D plot of the arm movement of two people as measured with the BrAMS' new sensors, with the green line representing motion. The person on the left has no tremor and completes the movement in a smooth arc. The jagged line shows that the person on the right has significant intention tremor.

to the brain; and the other over the muscle responsible for dorsiflexion (bending the foot upwards at the ankle).

WalkAide offers several innovative features. The device is tilt-activated and uses electrode locators and an alignment indicator. A built-in inclinometer measures angular changes while an accelerometer measures velocity (the time lapse between angular changes).

The clinical trial for WalkAide ran from January 2010 to March 2011: of 50 people assessed, 31 were deemed suitable for the three-month home trial. Before using WalkAide, 100% of these patients reported tripping daily or weekly and 25% reported frequent falls. Within 12 weeks of using WalkAide, patients' perception of their walking ability increased from an average 4.3 out of 10 (without using WalkAide) to approximately 8.8 (when using WalkAide), using a visual analog scale (VAS) where 0 = walking at its worst and 10 = walking at its best. No patients in the trial experienced any trips or falls while wearing the device, and all said it was comfortable and easy to apply. In a nine-month follow-up with those who maintained continual use, patients' perception of their walking ability remained at a steady 8.1 when wearing the WalkAide and 3.8 when not wearing the WalkAide (VAS scores) .

Each WalkAide device is programmed by a trained therapist to reflect the needs of the individual patient, accommodating for personal gait and other factors. Despite its demonstrated efficacy, funding for the WalkAide remains limited by the National Health Service in the United Kingdom. Physiotherapists at BrAMS recommend a free home trial to verify that it is right for the patient before they apply for funding or self fund. A major benefit to PwMS is that WalkAide can be worn barefoot or with light footwear unlike other FES devices that require a sensor in the footwear and firm fitting shoes.

The MS Unit in conjunction with the University of Bristol is also exploring intention tremor, the shaking of a limb that often occurs when PwMS attempt to perform purposeful movement. The tremor often worsens as the individual

10 metre timed walk

At 3 months (end of home trial)

Time (seconds)	without FES	with FES
Range	7- 77.2	7.6- 61.8

Footdrop case study

A 37-year-old female, diagnosed with MS in 2006, began having problems walking as long as five years before diagnosis. A fitness instructor (teaching dance and drama) and mother of a young family, she feels it vital to have full mobility at all times. Within normal parameters, this woman is a fast walker, clocking in at 1.4 metres per second. With the onset of fatigue, she demonstrates worsening symptoms, becomes at risk of trips and falls, experiences a vaulting gait, and suffers pain in the neck and between her shoulders. Videos show that she has great difficulty in moving the leg forward to walk normally, and her gait becomes slow. After applying the WalkAide device, the patient is seen with no visible signs of footdrop and her gait restored to its normal pace. The increase in patients' quality of life from this device is significant, and no adverse side effects have been recorded.

approaches or reaches the target. The condition is rarely seen when PwMS are at rest (as opposed to the constant tremor exhibited in patients with Parkinson's Disease).

Intention tremor is caused by demyelination in connecting pathways between the thalamus, basal ganglia or cerebellum. One study (Alusi, 2001) shows that approximately 30% of PwMS have tremor severe enough to impede activities of daily living (e.g., using mobile phones, ATMs or computers, performing self-care, dressing or cooking); about 10% of those affected have incapacitating tremor.

Currently, there is no satisfactory treatment for this symptom. Moreover, it is impossible to quantify tremors from visual assessments. The research team in collaboration with the University of Bristol has been working to develop a clinically useful tool with sensors that make it possible to track the points at which the tremor occurs. The tool uses surface-worn sensors to measure arm movements during functional tasks in order to:

- Provide objective and detailed assessment;
- Measure extent and location of tremor; and
- Measure effectiveness of interventions.

The Team's findings show that tremor in PwMS exhibits a rhythmic frequency (usually 3 Hz to 8 Hz) and frequently occurs with muscle weakness and ataxic movements. Early study results confirm that the measuring device can help to dampen tremor at the elbow during purposeful movements. While the test model is basic in design and quite cumbersome, they will use this prototype to develop a streamlined tremor-control system that can be worn under clothing. The device showed no adverse side effects.

Funding for these projects has come from several sources: the EU Fifth Framework Programme (FP5); the NIHRi4i Innovation Fund; the Engineering and Physical Sciences Research Council (EPSRC) and the MS Research charity. The BrAMS Centre is grateful for the support of all participants and carers. Laurence Ketteringham, the key engineer in tremor studies was awarded Researcher of the year by the UK MS Society in 2010.

Workshop Summaries

The Importance of Symptomatic Treatment Options for PwMS

Teresa Pointer, PwMS, UK

Peter Flachenecker, MD Assistant Professor, Head of Department Rehabilitation Centre Quellenhof, Germany

My MS symptoms started in 1997 and included loss of feeling and sensation in my lower body and limbs, pins and needles, muscle tightness aches. I also experienced problems with balance, vision and bladder control, as well as fatigue and difficulty sleeping. Over the years, I saw numerous doctors and underwent many tests. In 2004, I was finally diagnosed with Relapsing and Remitting MS.

I've tried many different treatment options, many of which have provided great relief for my symptoms. Physiotherapy is helpful and I enjoy the stretching exercises. Meditation is good too, and helps me to relax. It's important that all patients explore a wider range of treatment options: medical therapies can be complemented by more alternative therapies that work for each individual. Everyone has different needs and responds differently to particular treatments.

About six years ago, I read in a local newspaper about Sativex, an oral spray medication that was part of a new drug trial for treatment of spasticity in PwMS and applied to be included. I started using Sativex in 2005 and it has proved very beneficial to me. Although Sativex was licensed in the United Kingdom in 2010, there are still problems getting it prescribed.

Denmark: Successful Fundraising on National, Regional and Local Levels

Helle Ousted, Fundraising Manager, MS Society of Denmark

The Danish Multiple Sclerosis Society (DMSS) develops fundraising programmes across the country, working from the smallest community to the national level in order to raise both awareness and funds. The Society's motto, "your pennies will take us far", inspires its working relationship with businesses, organisations and the general public.

The collection box is an excellent and very basic tool that can be used in a variety of ways. In Denmark, a society cannot go from door-to-door asking for money, so placing a collection box at the cash register of local shops and big chains is a way to reach a very large audience without asking those businesses or their customers for money directly. It also builds valuable relationships with both the owners and customers of the shops.

In 2008, the DMSS organised one of its largest campaigns. At the time, the Danish Mint was taking steps to eliminate the seven-cent coin from the currency. The Society had the idea to ask the public to donate these coins to its cause, knowing that it would be possible to take the coins to the bank to receive the value. By the time the government took the coin out of circulation, the DMSS already had press coverage about the campaign and people responded very positively. Some 15 000 shops placed a collection box at their tills and the Society raised EUR 900 000, which led to more media coverage. This visibility significantly increased public awareness of MS.

Sponsored events allow people to donate money to a charity while participating in an event they would partake in regardless. The DMSS

capitalised on this idea with a Zumba [01] event, held in February 2011. The "Zumba for MS" evening was run by a trained Zumba instructor who had contacted the Society wanting to raise money for charity. Here the event itself is the attraction: 200 participants paid EUR 25 each for a three-hour event and all proceeds went to the DMSS.

To capitalise on the momentum created by an event, MS societies should consider asking other companies to match donations made, running an auction or lottery at the event, or selling refreshments that have been donated. Afterward, it is vital to maintain the contacts established and thank the organisations that helped facilitate the events. It is also a good idea to contact the press with specific details of how much money was raised and how it will be used. Most importantly, find a way to personally thank all event participants: send personal emails and follow up with a phone call, presenting an easy way for them to continue being donors.

The DMSS recently created the "Member with MS Gets Members" concept, using its own database of PwMS to build up membership in the Society. At present, the total number of members and donors in the Society is 60.000, including about 8.500 PwMS (it is estimated that the total number of PwMS in Denmark is 10.000). The DMSS asked all members with MS to provide contact information of people they know who might want to become their personal supporters. When the campaign was first launched, there was a 4% return on the form, which equalled 1.570 new addresses and a 20% increase of members. Five years later, 70% of these people are still members or donors and 105 had upgraded to pay monthly by direct debit.

As the DMSS has shown, a lot of pennies and a lot of individuals can make a big difference!

[01] *Zumba is a fitness craze that uses high-energy Latin music.*

Fundraising in Belgium

Antoine Gebara, Member of the Belgian National MS Society, Belgium

In the French-speaking area of Belgium, 65% of the income of the MS Society is obtained through the sales of chocolates. This initiative started in 1985 in Liège Province, where the Galler factory is established. At the time, Galler was a small family enterprise that gave the MS Society a very interesting price on chocolate it could then re-sell. In just two or three months, the Society sold 50 tons of chocolate! This helped Galler to become a large company and, in turn, Galler helped the MS Societies to gather a large sum of money. These funds are used to help Society members participate in activities such as mini-trips, vacations on the seashore, excursions, etc. It is also used to reimburse PwMS for extra charges due to the disease such as family helpers, medical care, nurses, medicine, physiotherapy, etc.

The Society must acquire authorisation from several ministries and from supermarket managers to sell at shop entrances. We also need hundreds of volunteers for the sales in other locations (churches, schools, pharmacies, bookshops, etc.), but the results are great! Graciously, Galler accepts to be paid in October after the September campaign, which allows us to avoid having to advance the cost of the order. We are also allowed to return 10% of the order if not sold by the end of October.

The Flemish area has developed an auto-financing programme that accounts for around 80% of its income. As all NGOs are professionalising their fundraising systems, the competition to acquire a portion of the charity market has become very stiff.

MS Liga is identified with the selling of chocolates, which is heavily supported by the volunteers – many of whom devote their time even at the age of 65 to 70 years! We are now considering diversifying to sell products other than chocolates.

We also use mailings twice per year, and we participate in legacy campaigns, cycling, races, walking, golf and music for MS activities. We also have support from service clubs such as Rotary and Lions.

Patients' Organisations and Industry Donors: Building a Sustainable Relationship

Jean-François GRENIER, MD, CEO, PharmExpand SPRL, Belgium

A partnership is an arrangement in which parties agree to co-operate to advance their mutual interests. It can greatly benefit individuals, entities and societies, but can also greatly damage partners if ethical issues are not properly addressed. Bribery and conflicts of interests should be avoided, of course, in the interests of a sustainable partnership. Patients' organisations can establish sustainable, ethical relationships with companies to the mutual benefits of the collaborating parties.

Numerous pharmaceutical companies support EMSP on a regular basis, even though EMSP must avoid being perceived as helping those companies sell their drugs. The most important thing to decent people in the pharmaceutical industry is ensuring that patients get the best possible treatment. In today's environment, industry has not only a moral but also legal and financial obligations to demonstrate that their drugs are promoted and used appropriately, to the right patients and in the right way.

Sustainable relationships require two-way collaboration; organisations should know what companies want and expect from them – and organisations need to be clear about what they will provide in return. For instance, industry donors want to understand patients' perspectives on the disease and help patients improve the quality of their dialogue with physicians, particularly with highly trained specialists. Companies also want to recruit patients for their clinical trials, obtain reimbursement for their latest product and maximise compliance to treatment. Of course, they also want to sell their products.

When patient organisations explore potential partnership, it is best to have long-term goals. Identify areas in which both parties may benefit from collaboration; have a candid discussion with industry counterparts about each party's objectives; and compare and contrast goals, identifying precisely areas of common interest and programmes that could be run jointly.

Areas of common interest between EMSP and pharmaceutical companies are numerous, and include: well-being of people with MS; understanding of MS and the need for treatment; developing new and more effective treatments through rigorous clinical trials; and educating patients, families and physicians. An important way to appear less tied to pharmaceutical companies is to diversify sources of funding to include other industries such as devices and diagnostics.

Clarity and transparency are vital: partnerships must be built on trust, yet also preserve integrity and independence. This includes the need to behave in a business-like manner by being prepared for meetings, writing minutes, having contracts, respecting partners and following through on commitments.

Health Technology Assessment: What Do I Need to Know as a National Patient Advocate?

Laura Sampietro-Colom, MD, PhD, Deputy Director on Innovation, Hospital Clinic Barcelona
President, Health Technology Assessment International, Spain

Health Technologies: Purpose or application

- ***Prevention:*** protect against disease
  - Eg. Immunization, hospital infection control program
- ***Screening:*** detect abnormality, disease or risk factor
  - Eg. Tuberculin test
- ***Diagnosis:*** identify the cause of disease
  - Eg. X-ray for possible broken bone
- ***Treatment:*** improve or maintain health status
  - Eg. Coronary artery by-pass, psychotherapy
- ***Rehabilitation:*** restore, maintain or improve disable's person function
  - Eg. Exercise program for post-stroke patients

Health Technology Assessments (HTA) are undertaken for all types of technologies including: medical devices, equipment and supplies; medical and surgical procedures; drugs; support systems; biologics; and organisational and managerial systems. The aim is to ensure the technology delivers its claims in relation to improving health (see slide) in a specific health care context; thus, the usual period for assessment is when the technology has advanced beyond an experimentation stage into an investigational phase. Technologies that do deliver often go on to become established standards.

An HTA is a research-based, practice-oriented assessment of relevant available knowledge on the direct and intended consequences of technologies, as well as the indirect and unintended consequences. Its goal is to provide input to decision making in policy and practice. It combines global and local scientific evidence and other information to assess performance, safety and efficacy, effectiveness and appropriateness of use in a given context. Ultimately, it seeks to answer three questions: Can it work? Can it work here? Should we do it here?

The complexity of the HTAs process – which typically involves weighing technical, economic, organisational and ethical/legal considerations –

for informing decision-makers, is often difficult for non-experts such as patient advocates to comprehend fully.

Patient advocates need to understand the importance of context in HTA recommendations, and the fact that the final decision depends upon decision-makers who consider other additional factors besides HTA recommendations, such as policy agenda, experiences and resources, with values being a central element. At this level, in the final decision, decision makers may also investigate factors such as need, available alternatives, innovativeness, burden/severity of disease, relevance for public health and equity to decide in final coverage/reimbursement of the technology. This helps to explain why a technology may be adopted in one country or region, but not in another where more cost-effective alternatives are available, or societal values favour a different approach.

The HTAi (the International Society for HTA, www.htai.org) is a network of more than 1 200 individuals plus 48 not-for-profit and 16 profit organisations. Under its activities there are 10 Interest Sub-groups, which is where patient advocates fit in. Although the input of patient advocates is relatively new, it is vitally important. Individuals who grapple with the many details described above need to be reminded that, in the end, these technologies are designed to improve quality of care and quality of life for patients. The HTAi is committed to continuing to find ways to strengthen the relationship with patients and assist them in better contributing to the assessment process.

Patient Involvement in HTA: What Do I Need to Know as a Patient Advocate?

Liuska Sanna, Programme Manager, European Patients' Forum, Belgium

Real-life evidence is the most vital contribution patient advocates can make to the HTA process. Being the only interest group that can speak from the position of having experience with the disease, patients can educate other experts on areas such as: symptoms, limitations and pain; impacts on daily life, work, social life, and leisure activities; and impact on mental health.

This makes patients well positioned to give key insights into the impacts of new technologies undergoing assessment. Patients can provide key information about:

- Needs and expectations
- Benefits and expected outcomes
- Unwanted effects
- Financial implications

Many challenges remain in making the role of patient advocates more effective. The HTA itself recommends that patient advocates be proactive in approaching agencies and educating them about the patient perspective; they should also establish contact with other patient organisations that have already gained experience in the HTA process. Patient organisations should also build relations with decision makers, particularly seeking greater accountability and transparency, the presence of patient advocates on committees and boards, and the opportunity for patient advocates to particpate in review processes of HTA reports. They should also initiate and participate in public debates about the introduction of new technologies.

Patient advocates should not shy away from asking patient organisations or HTA agencies to provide financial support for training and for their participation. A recent survey undertaken by the HTA identified three key challenges (among others) that require mutual effort: lack of an agreed and good method for participation; the need to improve the credibility of patient evidence; and a lack of capacity on the part of the HTA to include patients.

More information about patient involvement in the HTA process in Europe is available at: *http://www.eu-patient.eu/Initatives-Policy/Initiatives/*

EMSP Youth Congress 2011 Report

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Acknowledgements

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EMSP would also like to express its gratitude to all sponsors and partners for their continued commitment to support EMSP. Thank you to everybody who made this Youth Congress possible and a great experience!

Introduction

Shana Pezaro, UK,
chairwoman of the EMSP Youth Congress 2011

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.

Following the great success of the first Youth Congress in 2010, the second EMSP Youth Congress took place on 12 May 2011 in Brussels. There were twenty participants from fourteen European countries: Belgium, Czech Republic, Estonia, France, Ireland, Italy, Latvia, Netherlands, Norway, Poland, Romania, Spain, Sweden and the United Kingdom.
This year, 2011, there were four main topics discussed during the Youth Congress.

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.

YPwMS and MS Societies
The final discussion table focused on how each country's MS Society involved YPwMS. There was further discussion about what YPwMS expected and actually needed from their MS Society.

Networking for Young People with MS
Discussions took place about the importance of networking through both social media and face to face interaction for YPwMS. Discussions included how to set up such networks, how to maintain and monitor these networks and what they could achieve.

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.

It is very important that the information and ideas shared at the Youth Congress are reported back to the National MS Societies in order to directly influence their work with young people in the future.

The Youth Congress is an excellent starting point to come together in one place to share information, but participants all believed that there would be a great benefit from ongoing support and discussion. There needs to be an effective way of communicating as a group throughout the year so participants can continue the excellent discussions and idea-sharing started at the EMSP Youth Congress.

The 2011 EMSP Youth Congress was a great success and a springboard for many further discussions and initiatives in the participants' respective countries. Everyone is looking forward to meeting again next year.

Information and Young People with MS

Emma Rogan, Board Member, MS Society of Ireland

Where to get information?
Primary sources of information for YPwMS include doctors, neurologists and other healthcare professionals. In Norway, a two-day course for newly diagnosed people includes participation by nurses, doctors and neurologists. People can bring a friend or their partner. This multi-disciplinary approach provides a means for YPwMS to discuss their condition in a safe environment.

Participants spoke about the amount of verified and unverified information online which makes it "difficult for people to make correct decisions or know whether information is reliable." Social media sites such as Facebook are great for YPwMS to connect with one another. However, we all experience information overload. How do YPwMS decide what is right for them? MS societies can provide direction and some stability in terms of reliability of information.

The possibility of having an interesting website with information booklets, events, regional conferences and support was discussed. It would include information about weekends for newly diagnosed, events for partners and family members and provide the opportunity to speak with other PwMS.

Which kind of information?
Some YPwMS do not want to know negative information. However, people do want realistic information about their options. Also, information presented in a manner that respects the individual's situation (i.e. a patronising neurologist who does not take time to discuss options or who withholds information) is discouraging and damaging.

YPwMS want information about disclosure of their condition to family, friends and employers; their rights and/or protection in employment (law, issues of constructive dismissal); having children; how to manage relationships, issues on sexuality and services available.

Everyday management strategies are a means of empowerment, enabling YPwMS to make decisions and live to the fullest of their capabilities.

Newsletters, online forums and emailing lists are all cheap ways for YPwMS to get reliable information. Some societies provide newsletters and magazines by post.

When YPwMS get together they can share experiences, information on treatments and management. Young people are generally less conservative and want to discuss problems they're having with relationships, their sex lives and other personal aspects that older people living with MS are not used to discussing. If MS Societies are not comfortable facilitating such discussions, the Society should provide facilitators who are.

Information and Young People with MS

Ann Piecha, Member, MS Society of Poland

When young people are diagnosed with MS, they have particular concerns and questions: How will my life change? Will I have to adapt my activities? Can I have children? Can I continue to work? What kind of treatment is available?

Most YPwMS use the internet as their primary source for accessing information about MS as it is the quickest and easiest means. The main problem with the internet, of course, is the lack of credibility: much of the information published online has no editors or fact-checkers. Information is only reliable when the sources are credible, such as pages created by MS Societies, government agencies, or forums in which people can share questions and answers. Even in forums, though, information must be filtered as one person's experience can differ from another's.

Many newspapers and medical journals also offer a means for YPwMS to learn about MS. These sources are highly reliable and often publish information about the latest medical treatments, technologies and equipment that may help address the everyday difficulties of living with MS.

Delegates at the Youth Congress unanimously agreed that a mailing list should be set up to disseminate current, relevant information. In addition to making it easier to obtain reliable information, a mailing list would also give YPwMS a chance to share with their peers on many topics – including their fears, feeling, troubles and solutions.

Young People with MS and MS Societies

Shana Pezaro, MS Patient, UK

Involvement of YPwMS

Often MS Societies/branches say, "We tried setting up an event for young people but they didn't come. So they evidently don't really need/want it". However, many participants had examples of very successful youth events. It was felt that often MS Societies do not properly ask young people what they actually want. And MS Societies can easily 'give up' on young people. YPwMS often do not want to attend branches or events with older people.

Most countries do not have a central budget for YPwMS. Therefore, it is regional branches or organisations that have the responsibility for organising events and support for YPwMS. This means that provision for Young People is very variable, and is dependent on where they live. There is not a consistent support network throughout the country. Italy is trying to organise groups for YPwMS in each region as well as a national programme: this is an excellent example of good practise.

Countries such as Denmark and Italy have 'Youth Councils' as part of their National Organisation. This seemed to be a really good way of engaging YPwMS with the MS society and guiding the MS society about what they want.

Participants discussed the importance of not only involving and supporting YPwMS, but involving friends, families and partners in activities and information provided by the MS Society.

YPwMS's needs

YPwMS need their MS Societies to provide accurate information designed specifically for young people about: employment, sex, continence, relationships, benefits. Many participants felt their MS Societies did not fully recognise why information, guidance and support about these issues were different for younger people than for older people.

YPwMS need their MS Society to provide website information specifically for young people and the opportunity to create network and get peer support through discussion forums and facebook.

YPwMS want their own events such as photography courses, going to pubs, gigs, restaurants etc. They want the MS Society to enable them to make friends whilst actually doing an activity – not just sit around together in a branch talking about MS.

Young People with MS and MS Societies

Emma Rogan, Board Member, MS Society of Ireland

Involvement of YPwMS

MS societies across Europe have trouble engaging with YPwMS, perhaps due to the historical ways and means of working with and for PwMS. Now, it is not only about giving information to YPwMS; MS Societies need to ensure the channel for information is open to information flowing back to the societies. If there is a constant exchange of ideas and information it gives everyone a stake in the society, strengthening it now for the future.

Involving YPwMS in their MS Society means engaging with YPwMS as partners rather than as clients. Participants feel that MS Societies are afraid of the changes that need to take place, but YPwMS are also cautious of engaging with their society. By learning from mistakes (lack of communication and participation), new ideas, stronger connections and a revitalising of MS Societies will take place. YPwMS are the future of the MS societies but YPwMS must also be willing to learn from the experience of others.

In the United Kingdom and Ireland, local branch structures create a disjointed approach. Local branch meetings can be unappealing for YPwMS (too much bureaucracy, generation gap). Some branches have events including day-trips and family outings but these are not arranged in all branches, and some YPwMS never have the opportunity to take part. This inconsistency is something national societies need to change for YPwMS outside of the active branches.

Some YPwMS don't want to be involved or participate in the Society events. They want reliable information but do not want the personal connection with the society.

Events

National Conferences: A conference for YPwMS was held in The Netherlands with more than 400 participants. This September, in Dublin, Ireland, YPwMS will have opportunities to meet one another and create groups for young people around the country. There must be follow-up by the societies and the enthusiasm of participants should be used to further network.

Social Events: Participants want MS Societies to provide the space and time for YPwMS to meet. A participant from Norway told of pizza nights, movie trips and local networking events that have been very successful. The Norwegian society also had a trip to the Canary Islands for 40 YPwMS, people who are still meeting and supporting one another. If the society provides the opportunities for people to get together then they will engage with one another and thus strengthen the society. A social group run by and for YPwMS in a local coffee shop/pub is low cost and provides a safe space for people to get together and talk.

Networking for Young People with MS

Inès Grau, Volunteer, MS Society of Spain (FELEM)

Social networking is an incredibly powerful and useful tool: it is accessible, easy to use and provides a means of instantaneous communication with no geographical limits. YPwMS can profit from social networking devices to contact their peers, promote awareness of MS, and share experiences and information.
Participants in the EMSP Youth Congress unanimously agreed on the importance of finding useful and reliable sources of information, which can be difficult when faced with the sheer quantity available on the internet. Official websites, forums and networks devoted to YPwMS help direct people to trustworthy sites where information is carefully researched and edited.

Exchanging experiences with their peers helps YPwMS feel understood and supported by a network of people in similar situations. The potential for anonymity is another positive aspect of online networking, as many YPwMS would prefer not to publicly identify with their disease. It is not easy to deal with a diagnosis of MS and online networking can be useful to find relevant societies, groups, activities and people. Networks for YPwMS should take into consideration their particular needs, concerns, fears and questions. These networks should be a place where people feel comfortable expressing their feelings and thoughts without being judged.

When creating an online network for YPwMS, it is important to consider what information the users would like to have posted and what services they would like to see offered. A YPwMS would be the perfect candidate for the role of network moderator, as he/she may be more attuned to the needs of users. Doctors, psychologists and researchers could be involved in the creation of such a network and provide regular updates on treatment options. Online networking can be used in a variety of ways:

- Promote awareness of MS around the world;
- Promote fundraising events related to MS;
- Allow YPwMS to contact and discuss with their peers, with the option of remaining anonymous;
- Help friends and families of YPwMS find information relevant to them as support figures and care givers.

Fundraising by Young People with MS

Camille Mariano, Member, MS Society of France (UNISEP)

The reality of a youthful, active YPwMS contradicts the stereotypical image many people hold of PwMS as severely handicapped, whether the person still has full mobility or not. The fact that many PwMS are young and dynamic can be an excellent asset for fundraising for MS societies as it attracts attention and challenges expectations. At the second annual Youth Congress, held in conjunction with the EMSP Annual Congress (12 – 13 May 2011, Brussels), youth delegates from participating countries expressed their own potential to facilitate and catalyse fundraising for MS.

A round-table discussion produced many fruitful, inventive ideas of ways to raise funds. The delegate from the UK suggested organising a poker tournament or a concert with popular bands, and the Italian delegate had the idea to coordinate a photo exhibition. After the exhibition, the photos would be auctioned off with all funds going to the MS Society. This idea has a lot of potential: the show could be built around a particular theme, or the photos could be taken by PwMS. Several delegates suggested selling items such as apples or flowers – objects that are simple, inexpensive and cheery.

When the idea of organising a particular challenge came up, everyone responded very positively. Challenging group adventures, such as mountain climbing, have already proved to be greatly successful in terms of both fundraising for MS and empowering participants. All delegates at the Youth Congress expressed the desire to explore these opportunities further, saying that the challenge should be something “spectacular” in which all YPwMS can be proud to participate. There is great potential for international participation, bringing YPwMS from various European countries together with a common goal. Money raised from such a Challenge could fund research, as this is a cause that would eventually benefit all MS Societies.

Fundraising by Young People with MS

Shana Pezaro, MS Patient, UK

Funding of YPwMS Activities
Most countries have very little specific funding for programmes for YPwMS. Participants felt that YPwMS are often disengaged with the society as their needs are not met. Participants felt that the MS Societies / branches are short-sighted about their lack of provision for young people - the more YPwMS feel engaged the more likely they will be to get involved with fundraising for the society.

Where groups for YPwMS do exist, they can struggle to get funding from the MS Societies. For example, MS Societies are more likely to support specific 'activities' than to support transport costs for people to meet in a café or pub. There is a lack of understanding about what young people need. Participants felt that young people's groups should be funded by the national society, but young people should be involved in planning, organisation and extra fundraising.

Fundraising by YPwMS
YPwMS often want to involve other people in their fundraising events, not just people with MS. For example, charity gigs or concerts, are 'normal activities' which can involve everyone, not just events for PwMS. Young people should decide what fundraising events will work best with their peer group.

Social networking such as Facebook and Twitter can be used efficiently and cheaply to tell everyone about fundraising events.

There was a great deal of discussion about how to raise the profile of MS. Cancer, Aids and Diabetes charities have the media monopoly in many countries. In some countries there are big departments of the national MS Society dedicated to fundraising. In others, such as Norway and Belgium, the MS Society is funded by the government. So the nature of the organisation changes the way fundraising works and the way money is distributed.

Countries with National Service can utilise volunteers for their MS Society and fundraising activities.

In Italy, a major bank sponsors the yearly youth congress. Businesses can be approached for funding and sponsorship. There are also grants available - from lottery, for example Romania, Poland and the Czech Republic talked about the Education and Culture Grant. Czech Republic Young People's Group got money from the government and businesses to make a film about MS and raise awareness.

This image was painted by Young People with MS during the EMSP Youth Congress 2011.

Conclusion

MS affects all participants whether as a person with the condition, working for a national society or a volunteer. The discussions were broad, enthusiastic and gave everyone a chance to hear about experiences in other nations. Our lives are enriched when we share ideas and create 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.

EMSP Supporting Partners

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