

**European Multiple Sclerosis Platform**

**Annual Conference**

*3 – 4 May 2013 | Brussels*

*Better together*

**Sharing expertise and  
influence to improve  
access to treatment,  
care and employment.**



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# Plenary sessions

## **Welcome and introduction to the conference**

- John Golding, EMSP President

## **Session 1 – Championing the needs of people with MS in the European Parliament: a personal view**

- Mihaela Militaru, Advisor to Petru Luhan, Member of the European Parliament

## **Session 2 – Why rehabilitation matters for people with MS: an evidence-based approach**

- Prof Peter Feys, President of Rehabilitation in Multiple Sclerosis (RIMS)

## **Session 3 – What are the real choices?**

### **Therapy options for people with MS in 2013**

- Dr Jaume Sastre-Garriga, Deputy Director, Department of Neurology MS Centre for Catalonia, Hospital Vall d'Hebron

## **Session 4 – Advocacy in action – How access to treatment, care and employment can be improved, despite austerity by effective campaigning**

- Sir Nick Partridge, CEO of Terrence Higgins Trust, Vice-Chair of UK Clinical Research Collaboration

## **Session 5 – Citizens' Jury: Generics for the poor, new drugs for the rich – is this the way forward for sustainable healthcare for all Europeans?**

- Sir Nick Partridge, Chairperson,
- Dr Alexis Willett, Health Policy Expert, Facilitator
- Michael Kotsnis, Generic medicines: Synthon pharmaceutical company
- Brendan Barnes, Original medicines:  
European Federation Of Pharmaceutical Industry Association (EFPIA)
- Bettina Hausmann, Paul Mossman, Patients' perspectives

## **Session 6 – Progressive MS in focus – will there be access to improvements for people with progressive MS: Perspectives from the first progressive MS meeting in Milan**

- Antonella Moretti, CEO of Italian MS Society
- Ceri Angood, Multiple Sclerosis International Federation (MSIF)
- John Golding, President of EMSP

## **Session 7 – How MS Societies and EMSP can best work together to change the face of MS in Europe and launch of the Under Pressure Website**

- Anne Winslow, Vice-President of EMSP

## **Concluding remarks**

- Maggie Alexander, CEO, EMSP
- John Golding, President of EMSP

# Workshops

## Workshop 1

### **Building, supporting and equipping advocates for effective lobbying**

- Maria Mavris, Therapeutic Development Director, EURORDIS

## Workshop 2

### **How can we cooperate effectively with industry whilst maintaining our independence and credibility?**

- Alexis Willett, Founder and Chair of Punch Consulting

## Workshop 3

### **Positioning our organisations in influential policy-making bodies**

- Nicola Bedlington, CEO, European Patients Forum

## Workshop 4

### **Turning words into action – session for young people with MS to identify the priority programmes to deliver in partnership with EMSP**

- Emma Rogan, Youth Representative, EMSP Executive Committee

## Workshop 5

### **Keeping the door to employment open – Developing an Employers' Charter**

- Shana Pezaro, MS Activist
- Emma Rogan, Youth Representative, EMSP Executive Committee

## Workshop 6

### **Top tips for effective fundraising in a difficult economic climate**

- Christoph Lotter, Deputy Director, Swiss MS Society
- Aleksandra Baranowska, Urzuli Jaworskie Foundation

“EMSP is a meeting point; a place where we can exchange ideas; where we can absorb inspiration and connect with different people.”

*[Pille-Katrin Levin, MS Society of Estonia]*



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# Welcome and introduction

John Golding introduced a line-up of exceptional speakers: Ms Mihaela Militaru, Policy Adviser to Member of the European Parliament Petru Luhan, Professor Peter Feys, President of RiMS, Spanish neurologist Dr Jaume Sastre, Sir Nick Partridge, CEO of the Terence Higgins Trust and health policy expert Dr Alexis Willett.

EMSP's President then identified the main points of focus for the day's presentations and debates, namely: access to treatment and care, as well as employment for people with multiple sclerosis (MS).

John Golding stressed that, where appropriate, people with MS should try to start treatment as early as possible: "Treatment after a first clinically isolated symptom has been shown to delay the onset of active MS. Disease-modifying agents should thus be used as early as possible in the course of the disease, to avert or slow down the development of permanent disability."

John Golding said that he sees access to care as the process of "learning about MS, finding out about how MS is treated and identifying the right care". He suggested that people with MS shouldn't focus just on countering multiple sclerosis but on keeping themselves "generally as healthy as possible", as a recipe for achieving a better quality of life.

In referring to the topic of employment, EMSP's President said: "Although 95% of people with MS have a history of employment at the time of diagnosis, surveys of people 5 – 15 years later show fewer than 25% are working." John Golding expressed his confidence that, with minor adaptations to the workplace, many people with MS could do a productive job.

A person with MS, John Golding gave the audience a very personal dimension to his introductory speech: "I know that physical wounds can sometimes heal from the inside out. As cells and tissues regenerate, physical renewal can occur. Unfortunately this is usually not the case with MS. However, if my spirit is wounded I can be healed within. Our healing 'prescription' may include forgiving myself and others and may also call for tolerance and understanding."

# Championing the needs of people with MS in the European Parliament

## *A personal view*

Mihaela Militaru drew attention to the fact that many organisations concerned with health are not sufficiently informed about the full range of tools available for advocacy. Although this is not the case with EMSP – whose Brussels-team organised an Under Pressure photo exhibition in the Parliament last year, helping to persuade over 400 MEPs to sign a Written Declaration in support of the fight against MS – Ms Militaru took this opportunity to encourage organisations to continuously strive for more in relation to policy-makers.

“Why not be more ambitious and aim for a Resolution? The first step towards achieving this would require the organisation of a debate in the Parliament on an issue of special interest for people with MS – for example, ‘Improving employment policies for people with MS’. This would be an effective goal for the future”, said Ms Militaru.

Petru Luhan’s Policy Adviser then explained that in order to get a Resolution, an MEP must first make the proposal, which then requires the support of forty MEPs. While admitting that this is not an easy task, Mihaela Militaru reminded the audience that MEP Luhan successfully pushed for a Resolution on Digestive Cancer and added that “if you have influential MEPs associated with the proposal and you then lobby for support in the Parliament there is a good chance of success. You can start from Brussels and then extend your lobbying to the national level”.

Mihaela Militaru also suggested to the representatives of organisations involved in health issues that they should focus on getting more funding from EU institutions, adding that this requires good research in the first instance.

In the discussion which followed, Ms Militaru was asked if a resolution on ‘MS and work – focused on young people’, for example, would interest the Parliament. She replied that, until now, EMSP’s lobbying has concentrated on explaining what MS is and what the problems of people with MS are. But a new approach focusing on the politics of employment would be well worth pursuing, she concluded.



## Session 2



Peter Feys concluded that exercise has the potential to achieve some of the same benefits as disease-modifying drugs, amongst them – preventing deterioration. He also called for stronger advocacy for rehabilitation to counteract the perception by some that it is merely a placebo.

### Physical therapy matters – especially for young people with MS

“Physiotherapists should be involved from the start because the greatest potential for central nervous system adaptation and recovery occurs in the early stages of the disease. Physiotherapy intervention and advice early after diagnosis can reduce disability, maximise potential for independence, improve employment sustainability and reduce the impact that the disease has on health and quality of life factors” – UK Chartered Society of Physiotherapists

The question “what happens when people don’t want to exercise?” was raised in the discussion by Emma Rogan, EMSP’s Youth Representative: “We all go through times when we drink too much, smoke too much, when our mental health isn’t the best. So are you looking into behavioural changes?”

“I do see more interest in behavioural changes in two ways. One is the development of research and clinicians showing more interest; the second is that we see more interest and involvement from psychologists”, Prof Feys responded.

## **Why rehabilitation matters for people with MS**

### *An evidence-based approach*

Peter Feys focused on the role of exercise in rehabilitation in MS, which he described as an individualised process, aimed at reducing disability. He emphasised that rehabilitation requires patience and understanding, education and behavioural changes.

“People with MS often fear that exercise may make their situation worse and cause relapses. Recent evidence confirms that for the great majority of patients there is no increased risk of relapses as a result of engaging in exercise. Mounting evidence confirms that it is possible to obtain benefits in relation to physical activity, mood, quality of life and fatigue.”

Peter Feys recommended exercising in a specialised facility – it is likely to offer more motivation than training at home – and also timing the training, since the greatest results usually come during the first three months. Benefiting from qualified staff and proper infrastructure is very important for MS patients, added Prof. Feys referring to a study published in 2009, which asked people with MS “what they think about physical activity”. Other issues identified in this study were time management and fatigue.

Another benefit of exercise is the potential for improving patients’ perception of their own capacities. He gave an example of how to engage with MS patients in trying to promote the advantages of exercise: The Flemish MS Society had a programme in Flanders which included publication of sports and movement therapies in a journal and organising one-day events educating patients on benefits and barriers with regard to exercise, as well as direct experience of doing yoga, Pilates, football etc.

“We monitored 42 patients with MS of whom 18 said that they did not have visible abnormalities and 14 that they did have visible disabilities. All of them reported within 6 months of this event that MS had impact on their physical activities – but only those patients who reported no visible disability were able to increase physical activities. From these experiences with patients we conclude there is need to form a network of certified healthcare professionals reachable by people with MS.”

### What are the real choices?

#### *Therapy options for people with MS in 2013*

Dr Jaume Sastre-Garriga introduced his presentation by saying that there is “great hope for the future” in the fight with MS because of “significant progress on new oral therapies that decrease the frequency of relapse rates and delay disease progression”. “Oral drugs are especially welcome to long term MS patients who have been injecting themselves with interferon for so long they have trouble finding new injection sites”, he added.

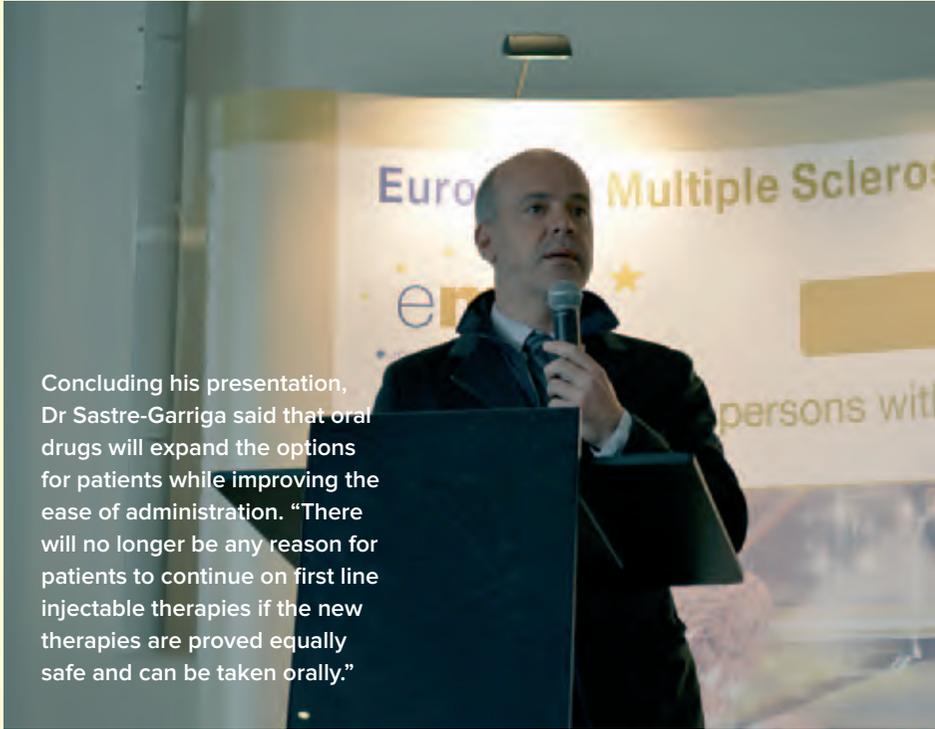
“There will no longer be any reason for patients to continue on first line injectable therapies if the new therapies are proved equally safe and can be taken orally.”

Dr Garriga then compared classic interferon treatment with some of the more recently available medicines.

First, he talked about Natalizumab: “We had been using interferons for years when we heard of this new drug, which clinical trials showed had twice as strong an effect on relapses compared to interferon. It is a very powerful drug but we still need to decide about what type of patients it should and should not be given to.”

On Fingolimod, Dr Sastre-Garriga reported: “Clinical trials showed its superior efficacy for reducing relapse rates, compared to interferon. However, safety concerns arose which called for continued patient monitoring. Consequently, Fingolimod is still a second-line therapy in countries governed by the European Medicines Agency, while in countries like the US or Switzerland it can be used in first line treatment.”

Other emerging therapies include Aubagio and Tecfidera, drugs which will soon be approved by the EMA.\* “Aubagio (teriflunomide) is an oral drug that was approved on the US market last September and whose effect on the relapse rate is similar to interferons. Tecfidera (Fumaderm) is also used in the treatment of moderate and severe psoriasis. The effect of this drug on relapse rates is also important, a boost of 50% compared to placebos, but there can be side-effects such as gastro-intestinal pains and diarrhoea.” Tecfidera is considered to be safer, more effective and less expensive than most alternatives.



Concluding his presentation, Dr Sastre-Garriga said that oral drugs will expand the options for patients while improving the ease of administration. “There will no longer be any reason for patients to continue on first line injectable therapies if the new therapies are proved equally safe and can be taken orally.”

“ I’m always satisfied when there are presentations on the latest MS therapies. This is good. I feel informed and this is what we are coming here for.”

Luiza Wiczyenska, MS Society of Poland

\* On 27 June 2013 The European Medicines Agency (EMA) recommended the approval of Aubagio – a 14 mg teriflunomide film-coated tablet and Lemtrada – a 12 mg alemtuzumab in 1.2 ml (10 mg/ml) concentrate for solution for infusion. Both medicines are for the treatment of relapsing remitting MS.

### Advocacy in action

#### *How access to treatment, care and employment can be improved, despite austerity, by effective campaigning*

“Advocacy in times of austerity calls for new and innovative responses for effective campaigning”, said Sir Nick Partridge in the introduction to his session. Sir Nick suggested that there is potential for the MS community to learn from some of the experiences gained from successful HIV/AIDS campaigning in the 1990s in the US and UK.

“There are both similarities and differences between MS and HIV. Currently, about 100,000 people live with MS in the UK – roughly similar to those with HIV. The average age for diagnosis is 35 years for both conditions. But there are important differences too. HIV is an infectious disease, which impacts specific communities, largely focused in urban areas – all of which MS is not. Crucially important, though, is the dramatic improvement which has occurred in drug treatment for HIV over the past 15 years and which begs the question – can MS now follow the same path?”, enquired Sir Nick.

Sir Nick reminded the audience that in 1987 there was only one drug available for HIV – which provoked demonstrations under the campaign slogan “ACT UP”. “As a result of successful campaigning, the speed of drug development accelerated achieving a real breakthrough by the year 1996 – when there was a 70% fall in HIV-related deaths in a period of 18 months. HIV was changed from a life-limiting to a long term, manageable condition.”

From this experience the concept of “public involvement in research” took on new life. The original idea belonged to James Lind, who was a pioneer of clinical research more than 250 years ago. Today, the James Lind Initiative (funded by the National Institute for Health Research) and the James Lind Alliance (JLA) bear his name. The alliance is a facilitator of priority-setting partnerships (PSPs) which bring patients, carers and clinicians together to identify areas of priority for research and respond to the concept of treatment uncertainty (the lack of updated research evidence on effects of treatment).

**Sir Nick summarised what can be learned  
from the HIV experience in the UK:**

- Mobilise personal, political, social and commercial media forces
- Maximise the voice of people with MS through campaigning web platforms
- Explore the exciting new possibilities for collecting evidence and sharing it
- Have an eye on the long term, but plan short term – flexibility is the key
- United we stand – hence the importance of allies
- And, never, never, never, give up! as Winston Churchill said.

Sir Nick made this link with MS: “The MS Society in Britain, which is now a member of the JLA, has launched a major new project called ‘MS-Register’, which is based on the JLA approach, i.e., ‘putting people with MS at the heart of research’. It is the world’s first register to combine information from people living with MS and clinical and National Health Service data. Over 10,000 people have joined the study so far.”

Sir Nick also highlighted another online data sharing platform, ‘JustLikeMe’, which launched its first online community for patients in 2006 and has now been extended to MS.

Mobilising in response to austerity programmes which threaten funds for disability is also the way forward for MS advocacy, stressed Sir Nick. He spoke about the Disability Benefits Consortium, a national coalition of over 50 organisations working towards a fair benefits system – a reaction to recent austerity reforms in the UK which aim to reduce the number of claimants by around 30%.

## Care, support and employment

- **UK welfare reforms** have the biggest potential impact – intended to save £8 billion and reduce the number of claimants by around 30%
- **Disability Benefits Consortium** - national coalition of over 50 organisations working towards a fair benefits system.
- **Hardest Hit** - the public-facing campaign against the disproportionate impact on disabled people of benefits and services cuts.
- **Worklife** - a web project to support people with chronic fluctuating health conditions in employment.
- **Care & Support Alliance** - calling for urgent reform to tackle the social care funding crisis.

Dr NICK PATRIDGE

**Sir Nick Partridge** – CEO of the Terrence Higgins Trust and Vice-Chair of the UK Clinical Research Collaboration

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Strong voice for persons with MS

## Session 5

### **Citizens' Jury: Generics for the poor, new drugs for the rich**

#### *Is this the way forward for sustainable healthcare for all Europeans?*

Generic medicines have been much discussed in the present context of Europe's rising health care costs.

Medicines only constitute about 10% of a country's total health care budget – with generic medicines constituting only 1-2 %. But they are a prime target for cost savings despite the fact that they are some of the most cost-effective elements in the health care system.

The role of generic medicines has been to provide essential medicines that are both high quality and affordable throughout the EU. Within the generics market, the highest utilisation rates are in Germany (75%), Poland (73%), the UK (71%), while the lowest can be found in Spain (41%) and Italy (40%).

Currently in Europe and the United States there are no generic medicines approved for MS. This is expected to change in coming years as patents expire on a number of commonly used MS medicines.

Against this background, EMSP organised a 'Citizens' Jury' to explore the issues involved. A citizens' jury is an event designed to discover what people think about a certain debatable issue. It allows participants to hear about the different sides of the debate and to question the evidence before voting on where they stand.

The Citizens' Jury explored the pros and cons of generic medicines, relying on a panel of experts who debated and engaged with the audience.

**Michael Kotsnis** – Generic medicines: Synthon pharmaceutical company

**Brendan Barnes** – Original medicines: European Federation of Pharmaceutical Industries and Associations (EFPIA)

**Bettina Hausmann** – Patients' perspective

**Paul Mossman** – Patients' perspective

Sir Nick Partridge – Chairperson

Dr Alexis Willett – Health Policy Expert, Facilitator



## **Perspectives on generic medicines**

Generic medicines have been developed to contain the same active ingredient as the so-called reference medicine and to be used in the same doses to treat the same diseases. However, a generic medicine's inactive ingredients, name, appearance and packaging can be different from the reference medicine. In the EU, all medicines are subject to rigorous assessments by medicines authorities before they can be authorised for use in patients.

As a result, these medicines offer patients the same high quality and efficacy, together with affordability compared to the originator. This combination has made them increasingly attractive for healthcare systems as a whole and patients in particular. Generic medicines can be marketed after the patent expiry of the originator product on which they are based. Every year, generic medicines save over €35 billion in costs across the EU27 because they are usually 20-90% less expensive than the reference medicine. Generic medicines account for over 50% of dispensed medicines in the EU.

It is therefore believed that if generic medicines were taken out of the health equation, EU healthcare systems would become financially unsustainable.

In February 2013, the EU voted on a new draft Directive to help patients get quicker access to cheaper generic medicines. It calls for a 60-day time limit for national authorities to decide on the pricing and reimbursement of generic medicines in order to speed up their availability and save money for patients and social security systems.

Generics may not be the whole solution, however. They are not necessarily available for all health conditions. In addition, as increasingly advanced new drugs are developed, generics may be comparatively less effective thereby increasing the health gap between those with access to the best treatments and those without access. There is need for balance between generic and branded drugs in health care systems. Patients' welfare must come first before short term financial targets in the field of prescription medicines.

## Perspectives from the pharmaceutical industry

A two-tier health service is already the reality today in many cases. With differences in the quality of care available to EU citizens in different member states. There are also differences within member states, particularly where certain forms of care are not reimbursed and where the only way to access a treatment is with “pocket payments”.

The pharmaceutical industry does not welcome the situation of two tier health system. In purely commercial terms, the industry is interested in ensuring that as many patients as possible get access to innovation at fair prices. Restrictions in access reduces industry revenues and ultimately has a negative effect on incentives for further research. The industry would prefer an approach to pricing which provides some recognition of issues of affordability. This begs the question, if patient needs and industry interests are aligned in trying to respond to affordability, what stands in the way of progress?

Who benefits from a policy that implies that all our member states can afford the same price? A burden has been added by the policy response to the financial crisis. This has emphasised a cost-cutting approach to health budgets which may have negative consequences in the short and medium-term. There has also been a focus on setting arbitrary metrics for the “right” amount to spend on healthcare. The consequences of these policies will be felt most immediately by patients, but also by the industry.

It is under-investment which is unsustainable, not access to innovation. Medicines often contribute to the overall efficiency of healthcare so by excluding more modern medicines efficiency improvements may be delayed. New sources of funding are needed and we need to look at the overall societal costs of ill-health and disability rather than focus on budgets for individual cost items. In a number of areas, including pharmaceuticals, but also IT we see massive potential to improve efficiency in health systems, but that requires investment rather than withdrawal. Our challenge is to make the case for increased investment right at the time when it seems the most difficult case to make.

**Bettina Hausmann**

Communication Specialist and MS patient



## Patient perspective: Bettina, who lives with MS

Living with MS is a lottery. Not only because people with MS do not know how their condition will evolve; but also because the care and treatment they get heavily depends on the country and sometimes even the region they live in.

Bettina explained that disease-modifying therapies can have an important influence on the course of MS, on quality of life, and on the contribution to society that people can make. All people with MS in Europe should have access to drugs that can help them live better with MS in the long run, and if generics can help boost access then Bettina would be in favour. However, it should be remembered that today's medication is good, but it is far from being good enough. There still is no cure for MS and the available medication can modify the course of the condition, but it cannot stop it.

Access to generics can by no means be an excuse to stop researching. On the contrary: now is the time to bring the best brains together to think about how all Europeans with MS can get access to the medication they need; and how to get closer to a world without MS. This requires not only investment and commitment, this also requires creativity.

“

Only when starting to support EMSP in their communications and advocacy did I realise what a privilege it is to have access to the best drugs on the market, and how many people in Europe do not have access to such treatment.”

Bettina Hausmann

## **Patient perspective: Paul, whose partner lives with MS**

Society has traditionally approved intellectual property protection (usually for 20 years) for pharmaceutical companies so they can earn profits and in return offer new and better drugs, plus a supply of cheaper generic copies after that protection expires. But the term “generics” is not applicable to the replacement of existing MS therapies, some of which are biologics and have to be replaced by biosimilars.

So, as the MS therapies reach the end of their initial 20 year patents, things are changing. Some biosimilars have already been approved. But the expectation that biosimilars will appear like cheaper generics is misplaced.

Pharmaceutical companies should recognise their impact on society, not just through the use of their products. “The term Corporate Social Responsibility (CSR) is not just nice to have – but rather is part and parcel of any 21st century industry’s licence to operate” (European Federation of Pharmaceutical Industries and Associations).

Four MS therapies came to the market in the late 1990s and by 2007 they were each grossing more than 1 billion Euros per year. What happened to their profits and CSR? What have they delivered? In addition to the four original Disease-Modifying Treatment suppliers, we now have more than 25 new companies trying to get into the MS market.

The situation for patients can get worse as the cost of new treatments continues to rise as they come to the market: The pathway for biosimilars is both costly and litigious.

A possible new solution? That at the end of normal 20 year protection, the industry takes a CSR decision to “generics-ise” their own products as newer and better therapies become available.



## Biological Medicines and Biosimilars

Biologics are a new class of medicines that have been produced through recent advances in biotechnology. They have transformed the lives of millions of patients with serious illnesses, including people with MS, and may be the best hope for effectively treating diseases for which there are currently no cures, like MS.

Biosimilars or follow-on biologics are terms used to describe officially approved subsequent versions of innovator biopharmaceutical products made by a different sponsor following

patent and exclusivity expiry on the innovator product. EMA's definition of biosimilars: "A biological medicine that is developed to be similar to an existing biological medicine (the 'reference medicine')."

There are, however, small distinctions in the cell line, in the manufacturing process or in the surrounding environment. All this can create a major difference in side effects observed during treatment, i.e. two similar biologics can trigger very different immunogenic response.

# International Progressive MS Collaborative – new hope for improved therapies

*Perspective from first meeting in Milan, February 2013*

Primary progressive MS is not very common – occurring in about 10% of all people with MS. People with progressive MS feel forgotten because most current research effort goes into the relapsing remitting form of MS (RRMS). Although treatment exists for MS symptoms, and rehabilitation can improve impaired functions and quality of life, there are still no disease-modifying drugs comparable to those that exist for RRMS.

There is now hope that this situation will be addressed by the launch of a major new initiative, the International Progressive MS Collaborative (IPMSC), whose mission is to expedite the development of therapies for effective disease modification and symptom management in progressive MS. The IPMSC held its first scientific meeting in Milan, in early 2013. The event was attended by almost 200 researchers and clinicians who discussed the challenges in identifying effective therapies and the many current efforts that are underway to tackle these challenges.

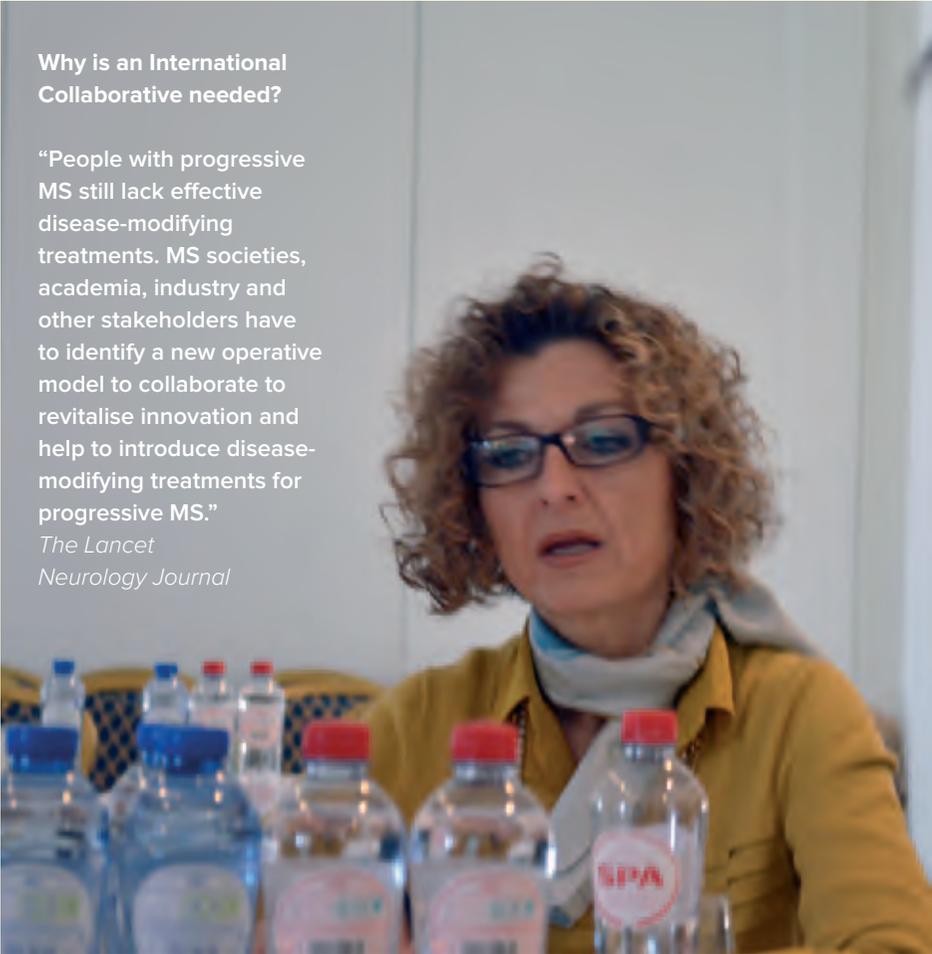
IPMSC has established its operating principles, which include: promotion of global collaboration in multi-disciplinary research; support the best research wherever it may originate and translate this research to the next stage to raise therapies for people with progressive MS.

The scientific leadership will now put forward an Action Plan to accelerate progress towards finding solutions for people with progressive MS.

### Why is an International Collaborative needed?

“People with progressive MS still lack effective disease-modifying treatments. MS societies, academia, industry and other stakeholders have to identify a new operative model to collaborate to revitalise innovation and help to introduce disease-modifying treatments for progressive MS.”

*The Lancet  
Neurology Journal*



“

We are addressing one of the most challenging aspects of research in MS: understanding and treating progressive MS.”

Professor Alan Thompson, Co-chair of Milan meeting

## MS patient perspective: John Golding, who lives with progressive MS

“I am a person with progressive MS. In 1982 the first symptoms appeared. I had problems of balancing and even vision, but I had no more noticeable symptoms until 1987 – when a neurologist made the diagnosis. Shortly after the diagnosis I became terribly depressed. I was in shock and in a state of self denial. Back then I used a walking stick – then I went onto crutches and finally I ended up in wheelchair already in 1992.

**In 1994** I suddenly had a seizure and was hospitalised for about a week and received 1000 milligrams of SOLU-MEDROL over a five day period (sterile powder which is an anti-inflammatory glucocorticoid used sometimes in cancer treatment).

**In 1995** I got involved in MS’ related activities.

**In 1998** I had a very hard work program with a lot of international travel my MS was taking its toll and finally I went on sick leave again with similar problems as in 1994 I went back to hospital but I refused treatment with a glucocorticoid as I was frightened of my previous experience. Sometime later, on recommendation from my neurologist and a multidisciplinary team, I changed my working life and went from a permanent post to becoming a consultant and professional non-executive board member in different companies. Full time executive work was no longer compatible with managing my disease.

**My perspective on the Progressive MS initiative.**

When I was diagnosed there was relatively little research. Today research into MS is a multibillion dollar business and more and better medicines are being developed and this should also bring hope for those with Primary and Secondary Progressive MS.

“ Emotional health is all important.  
My appeal: support the Progressive MS  
initiative and get involved!”





“ People with MS  
are not asking for  
charity, but for  
opportunities.”

Emma Rogan



# Workshop 1

## Turning words into action

### *Session for young people with MS to identify the priority programmes to deliver in partnership with EMSP*

This workshop aimed to advance EMSP's ongoing work programme that is designed to bring tangible benefits to young people with MS. In its 2012-2014 Strategic Plan, EMSP made a commitment to respond to the needs of young people with MS, who are disproportionately represented among those newly diagnosed with the disease. Recent conference discussions have begun exploring issues of special importance to young people. So, what are the next steps for turning words into action?

The workshop identified a number of issues of particular concern to young people including:

- employment – the benefits of work;
- advocacy – empowerment and personal development;
- education – self management and responsibility;
- relationships – when to 'come out' about your MS;
- self-management- keeping well and improving your health.

Participants agreed that there is now need for a series of activities to engage young people from the start in the selection, design, governance and delivery of a programme at the European level to be achieved through the EMSP platform and its networks. This programme could help to raise awareness of young peoples' needs, provide potential for access to key services and employment, be attractive to funders from a range of different sectors and encourage long-term sustainable relationships with new partners.

“ We believe MS doesn't mean giving up your ambitions, just rethinking how to achieve them.”

George Pepper, Shift.MS

“

This is an exciting time for young people with MS. Over the last few years, EMSP has been developing the capacity of young people by encouraging and facilitating us to take part, including the appointment of a young person on the Executive Committee.”

Shana Pezaro

Participants were asked to vote on a “shopping list” of ten possible initiatives that EMSP could develop in the near future. The main priorities were as follows:

- EMSP brokering internships for young people with MS across Europe;
- Treatment reimbursement provision applicable across the EU;
- Raising awareness of issues affecting young people with MS through European Year of the Brain (2014).

The workshop benefited from the contributions of two key campaigners for people with MS – Shana Pezaro and George Pepper. Both Shana and George are young people diagnosed with MS. Shana is an experienced political activist in her home town of Brighton, UK and has successfully influenced local policy on MS, for example in getting the Local Council to approve funding for a second MS nurse for the local MS community of 500 people.

George Pepper is the co-creator of an online social network which is dedicated to young people with MS, especially through the website – Shift.ms – that has 15,000 monthly visitors.

Participants supported the idea of EMSP working with Shift.MS to consult with young people about how best to develop its programme for young people.

## Workshop 2

### Building, supporting and equipping advocates for effective lobbying

Eurordis, a European non-governmental alliance of patient organisations committed to improving the situation of its patients through advocacy work, is the voice of 30 million people affected by rare diseases throughout Europe. Eurordis representatives or ‘patient advocates’ are extensively involved in the EU regulatory process.

Through its contribution to the European Patients Academy on Therapeutic Innovation (EUPATI), Eurordis aims to significantly advance the work of training patients in new drug development processes.

EUPATI believes that it is crucial for patients to be adequately trained so they can be at the table when clinical trials are designed and scrutinised and when decisions on access are made. Also of major importance in this context is how to facilitate partnerships between patients, researchers, industry and regulators.

The focus of discussion in the workshop was the involvement of patients in pre-clinical research, clinical research, regulatory processes and post marketing activities. The issue of building, supporting and equipping people for effective advocacy was also emphasised.

There is a need to train not only patients but also patient advocates. This means finding the right people for training and involving them from an early stage in the medicines development process. It also requires ongoing support and communication after training.

“ You know, even in economic terms, let’s put it bluntly, we haven’t got equality between European countries. In that sense it is even more important to feel involved in a greater whole. Together we are stronger, not apart.”

Olga Bobrovnikova, Belarus MS Society

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## Workshop 3

# How can we cooperate effectively with industry whilst maintaining our independence and credibility?

Pharmaceutical companies and patient organisations come together to collaborate in areas of shared interest. Evidence shows existence of widespread partnership in four main areas including financial support, healthcare policy, and increased access to medication and information to patients. That they should work together is an ideal – but it has raised some serious questions. This workshop explored the benefits and potential concerns of patient organisations in working with the pharmaceutical companies. The discussion included:

- the benefits of working with industry;
- barriers to effective partnership and possible solutions.

It is in the interest of patient organisations and the pharma industry to cooperate because of shared interests: pharma companies develop medicines for patients, they are part of the healthcare system and even if you don't engage with them the pharma industry will go ahead without you. However, there are concerns about how to work with pharma companies. Do they really listen to what patient organisations want? What kind of discussions do we want about research and clinical trials? How to define a good relationship? It would be characterised by transparency, honesty, financial support that is declared and recorded in an open manner. There would be exchange of know-how and a two-way flow of information.

### Relations between pharmaceutical companies and patient organisation

Pharmaceutical companies believe that if patients were aware that their prescription drugs could help them, their sales would increase. Advertising drugs to patients is not allowed, so companies try to inform patients in other ways. Patient organisations may welcome

financial and other help from companies. Such relationships must be at arms' length and transparent and not affect the agenda and priorities of patients organisations.

Andrew Herxheimer,  
British Medical Journal, 2003

Mistrust can arise from a number of factors. Pharma companies are increasingly engaging directly with MS patients, but their motivation may be very different from patient organisations.

Mistrust can also arise where there are information barriers and a lack of rules about agreements with companies. The solution is to have an industry code of practice.

Most countries have national codes of good conduct and these rules must be adhered to. But there is a very diverse landscape in Europe so all organisations must be brought together at one table. This shows the important role that an umbrella organisation can play by creating and disseminating rules. The EU has already published a ‘List of Guiding Principles Promoting good Governance in the Pharmaceutical Sector’ – without prejudice to any existing national legislation. There may be a further role for EMSP in this area.

“ The beauty about the way EMSP operates is that they work very much in the spirit of partnership. They are very open, transparent and collaborative. They stick to their code of practice and at the same time work very much in a partnership philosophy with the industry.”

Jean-Pierre Malkowski, Novartis

# Positioning our organisations in influential policy making bodies

As a pan-European body representing the interests of all patient groups at the EU level, the European Patients Forum (EPF) plays an important role in the European healthcare debate. Since 2005, it has established a sound track record of working on pharmaceutical regulation in the various European Medicines Agency (EMA) committees where EMSP is also actively involved. It has also played a key role in shaping the new EU directive on cross border health care which codifies cross border patients' rights to access health and be reimbursed. But more needs to be done to achieve better quality care for all patients.

This workshop discussion addressed the critical factors for successfully engaging with policy makers as well as the barriers that arise in the process. Critical success factors include timing, having a clear strategy and workable goals. There is need for consensus and a unified policy position. Hard work and tenacity is required as well as collaboration with other groups and knowing when to compromise. Barriers include the lengthy process of making contact and engaging with policy-makers.

A series of recommendations can be made to patient organisations working at the European level and to national societies on how to enable more effective engagement with policy-makers:

- Use European advocacy models and translate them into a national context: there is need for more strategic, sophisticated methodology to link EU and national advocacy; transfer of best practice to the national level should be accompanied by a strong focus on coalition-building.
- Work with powerful, evidence-based messages: the MS message is more powerful if you can use patients and their real life evidence. It is good to have people with MS as ambassadors – which EMSP already has with John Golding; gathering and creating patient-centred evidence is important with a strong focus on the economic and social impact of health care; present arguments with proof and passion; draw inspiration from other players, for example Nick Partridge on the HIV campaign;
- Education and training for external players in influential environments: explain what MS is about with a strong focus on non-discrimination and inclusion; use political opportunities and work with role models and champions.



“ I think one of the issues is empowering national societies to drive agendas themselves and to actually create more capacity building. It is about fostering an environment which ensures that advocates and champions of MS in that country have the knowledge, the capacity, the influence to be able to engage and to do what they need for themselves. It’s not about Europe posing at a national level; it’s about drawing on good experience.”

Nicola Bedlington

# Workshop 5

## Keeping the door to employment open *Developing an Employers' Charter*

Exploring employment options and making decisions about their career is one of the most important issues for young people as they are planning their future. Therefore, it is important to know what your employment options are and the keys for developing and achieving employment goals despite your MS diagnosis. Work can provide income, a sense of purpose, dignity and social connectivity for people with MS. But they have particular needs in terms of staying in employment – which require flexibility and adaptation in the work place. The cost of MS for society, in terms of employment loss and compensating social welfare, is increasingly recognised at national and European level, which should incentivise employers and governments to act.

The basic question to which the participants had to find answers and propose action plans was “how to help people with MS get and keep work?” Key concepts to kick-start the discussion were: access to employment; maintaining people with MS at work; fight against discrimination; adapting the workplace and consulting with employers. A special insight from Shana was that ‘employers need to see people for their talent and ability, not for their MS’.

The workshop discussed a possible future ‘Employer’s Charter’ for people with MS focusing on the following elements:

- There is need for funding to make employment available and accessible and some guidelines need to be created for this;
- There is also need to provide and centralise useful information on MS;
- Concentrate on education about MS by organising training sessions for employers and interventions with work colleagues;
- Adaptation should be viewed as a holistic approach – get authorities to help people with MS to adapt to their condition and be able to continue contributing to society. The work place must be accommodated to people with MS, for example by installing rest rooms and constantly demanding the rights of people with MS to be respected;
- 2013 is the European year of the Citizen so use advocacy as a tool to influence decision-makers to fight discrimination against long term conditions and gender;
- Make alliances with other European groups that have shared interests;
- Know your rights and the legal protection available to you.

Shana Pezaro – MS Activist

Emma Rogan – Youth Representative, EMSP



“ It’s also about what we can learn from people and it’s our responsibility to support and share ideas and help other countries that are developing. It’s everyone; it’s not just one country.”

Shana Pezaro, MS Activist, UK

## Workshop 6

### Top tips for effective fundraising in a difficult economic climate

The goal of fundraising is to provide the financial base for an independent patient organisation. Various sources of funding are available, including private individual donors, public funders such as national governments and the EU, private industry, events and activities, networking etc.

What is frequently missing in fundraising campaigns is keeping the message simple. It all boils down to one question:

Why should someone support you? This question is the key to successful fundraising in the current difficult economic climate.

But it should not be just you alone who knows why people should support your cause. Your team, your supporters and the people with MS in your country should know as well, and join in to convey your message.

World Vision India ran a very successful campaign with the message: **“Bringing hope where there is despair”**.

“ It’s really important to share ideas and encourage the countries that aren’t necessarily where we are in terms of campaigning and fundraising. They don’t all have those systems in place.

Shana Pezaro, MS Activist, UK





“ I think Under Pressure is marvellous. The whole making of the project was very educational – relating to people who were involved in the project who could help you with very personal stories, compare the situations, make you see how your country is maybe in not such a bad state and highlighting where we really lack knowledge and resources.”

Pille-Katrin Levin

## **How MS Societies and EMSP can best work together to change the face of MS in Europe**

Anne Winslow reinforced the conference theme of “Better together” and expressed her hope that EMSP and MS societies in Europe will continue to work collaboratively to make progress on the key projects for 2013.

EMSP’s Vice-President gave an introduction to MS Nurse Professional, a new, flexible e-learning curriculum, developed to meet the educational needs of nurses and other healthcare professionals providing MS care. It is aimed at nurses beginning their career in the field of MS. It is available in five languages (English, German, Italian, Spanish, Czech) and has been accredited by a number of recognised professional bodies including the International Council of Nurses.

The objective for 2013 is to launch the project via a sequence of events, starting with the roll out of MS Nurse Pro in the UK, which will be followed in other countries during 2013-2014. Next should be the publication of a Consensus Paper in the MS Journal, followed up by a presentation at the ECTRIMS conference in October of this year.

Anne Winslow also outlined EMSP’s priority activity and areas for collaboration with the national societies: “We can also work together on a number of other projects during 2013-2014. The Written Declaration by Members of the European Parliament will be further publicised on World MS Day and I urge you all to please try and convince any MEPs you know who did not sign. We will prepare an updated version of the European MS Barometer during the coming year. Work on the European Register project EUREMS which will provide essential cross-European data on MS and how people are affected will take new steps in 2014. An interim publication on EUREMS is in the pipeline. We are planning for closer co-ordination between EMSP – ECTRIMS – RIMS in the near future”.

Anne Winslow then revealed the brand new Under Pressure – website [www.underpressureproject.eu](http://www.underpressureproject.eu) – which opens up the entire resource of more than 500 high quality photographs, together with a booklet and videos – to all EMSP members.

## Concluding remarks

### **Maggie Alexander said:**

“This has been a really productive and motivating conference. We have benefitted from outstanding speakers and an extremely high level of participation and contribution from everyone here. I have found the personal testimonies particularly inspiring and I am extremely encouraged by the enthusiasm for our work as an organisation and most importantly, the commitment to even greater cooperation and collaboration between EMSP and our members in the future.

You have provided us with some very clear ideas about the direction of future travel and priorities for new programmes and I can give my personal assurance that we will give these our very close attention. They will definitely help to shape not only our future vision and strategy but also the programme for next year’s Spring conference, which will take place in Dublin, 2014.

I would like to thank everyone who has been part of this conference and particularly, the fantastic team from the EMSP Secretariat that has worked tirelessly to make this such a success.”

### **John Golding summed up:**

“It’s very helpful for ESMP to see clear themes emerge, particularly around a tangible programme for young people with MS; employment, continued emphasis on access to treatment and support for the Progressive MS Collaborative Initiative.

I very much appreciate the warmth, energy and enthusiasm so generously contributed by everyone who has been part of this conference and delighted that everyone has also had a chance to enjoy themselves, not least at the fabulous gala dinner and concert last night.”

“

I think it’s very important that we continue backing less well-off countries and enabling them to send representatives to the EMSP conferences.”

Elisabeth Golding (Norway)

“ We look forward to welcoming you in Dublin next year.”

“ This year’s conference confirmed for me the huge value of bringing people face-to-face to discuss and debate issues of interest and concern to them. We all benefited from the commitment and great ideas for the future that were contributed by all the participants.”

*[Maggie Alexander, EMSP CEO]*



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