

**EMSP 25th Anniversary
Spring Conference**
8 – 9 May 2014 | Dublin

Care where it
counts – as you
journey with MS



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

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John Golding, EMSP President 2010-2014 (speaking at the podium)



Welcome and introduction



“

I would like to commend the important job that EMSP does in bringing together multiple sclerosis societies from across Europe to work towards improving the life of people who live with this disease. It is by working together that we have the best chance of tackling chronic diseases such as multiple sclerosis.”

Commissioner Tonio Borg

As the outgoing President of EMSP at the Anniversary Spring Conference in Dublin, **John Golding** kicked-off the event by reminding an audience of nearly 200 stakeholders from the field of multiple sclerosis that EMSP is marking its 25th year of activity on behalf of people with MS in Europe.

John Golding, who was elected as President in 2010, thanked the attendees for their interest in the Conference and continuing support for EMSP's initiatives and went on to introduce the messages sent by two high profile invitees who were not able to join the Dublin event in person: European Health Commissioner Tonio Borg and past EMSP President Michael Willis.

In his video message, Commissioner **Tonio Borg** started by congratulating EMSP for representing the interests of over 700,000 people living with multiple sclerosis in Europe.

"I would like to commend the important job that EMSP does in bringing together multiple sclerosis societies from across Europe to work towards improving the life of people who live with this disease. It is by working together that we have the best chance of tackling chronic diseases such as multiple sclerosis."

The Health Commissioner emphasised the importance of EMSP's projects, mentioning that he looks forward to seeing the collaboration between this organisation and the European institutions continuing in the future:

"Accessible, high quality medical treatment and well-organised rehabilitation can significantly improve the situation of people living with diseases such as MS. EMSP has played an invaluable role in this respect – for example by disseminating the European Code of Good Practice in MS. The Commission is also pleased to have supported EMSP's European Register for Multiple Sclerosis".

The message from past President **Michael Willis** was shorter, but no less appreciative. His letter simply wrote:

"I am proud to be able to witness EMSP's great development as the one and only voice of more than 700,000 people with MS in Europe. I congratulate all of you who contributed to the achievements of EMSP over the past 25 years".

Both messages, enhanced by John Golding's introductions, were very well received by the audience and set the stage for what was described by one of the participants as "the best EMSP conference I have ever attended".

Opening Speech

Irish Minister of State for Disability, Equality and Mental Health, **Kathleen Lynch**, was invited to deliver the first speech of EMSP's Anniversary Spring Conference and it proved to be an excellent choice. Ms Lynch's warm demeanor and inspiring words seamlessly conveyed a key message: equitable treatment is essential in managing disability.

Minister Kathleen Lynch mentioned her personal interest in tackling multiple sclerosis at the very start of her speech:

"My niece has been diagnosed with MS. When a thing like this happens, you become obsessed with the respective disease area. And that's a good thing because that type of obsession makes you learn a lot over a short period of time. But once the calmness comes back into your life, you realise that things can be managed and managed they will be."

Ms Lynch continued by underlining that she considers "the part about equality" to be the most significant aspect of her portfolio in the Irish Government because "it ties all the others together".

"It should be our ambition that people with disabilities reach their full potential, that they have that expectation of themselves"; she stressed.

Kathleen Lynch also shared her own experience with disability: as a child of ten, she was hit by a bus and had to spend the next seven years of her life in hospital, "two of them on my back".

"That sense of helplessness has formed my view in regards to disability. No matter what, the persons in such situations must be heard. That hearing must shape our actions."

Minister Kathleen Lynch acknowledged that proper legislation is needed in order to "move away from the institutional approach". In this context she expressed her preference for a person-centered approach and individual budgets to enable more choices.

"We need to allow people with disabilities to live the lives that they want to live. We should not be the barrier in their way"; concluded Kathleen Lynch, before receiving a generous ovation from the audience.



“

My niece has been diagnosed with MS. When a thing like this happens, you become obsessed with the respective disease area. And that's a good thing because that type of obsession makes you learn a lot over a short period of time. But once the calmness comes back into your life, you realise that things can be managed and managed they will be.”

Irish Minister of State Kathleen Lynch



“

If they are delivered in a good way – rehabilitation trainings of 4 weeks, 8 weeks as well as daily training can really improve mobility, management of fatigue and cognitive resources. So today we can show that rehabilitation is effective.”

Prof Peter Feys

Prof Peter Feys

President of RIMS and Biomedical Department, University of Hasselt

The President of Rehabilitation in Multiple Sclerosis (RIMS), **Peter Feys**, is a steadfast partner of EMSP and his updates on rehabilitation practice and results have already become a trademark for EMSP's Spring Conferences.

With Day 1 of the Dublin Conference focusing on rehabilitation, Peter Feys responded to the challenging question "Is rehabilitation really working?" by citing a number of evidence-based papers.

Peter Feys referred to research results in two essential areas: cognitive and physical dysfunction. *"For cognitive dysfunctions you can run computerised programmes for memory, learning, attention and behavioural interventions, strategies that you apply yourself. The majority of such studies are saying that it is possible to have improvements in cognitive functions such as memory"*, said Prof Feys.

The RIMS President added that an Italian study on the effect of training on the brain structures showed that after 12 weeks of training there is indeed an increase in brain activity – focused on thinking, concentration and emotions. Peter Feys also mentioned that more than ten different studies during the past years have shown the importance of undertaking dual-tasking during rehabilitation – for example walking while talking. This is considered to support cognitive functions such as attention.

"For physical dysfunctions, many reviews have been published and everyone agrees that there were positive effects on muscle strength, endurance, walking and fatigue", continued Prof Feys.

He quoted a RIMS study involving 290 people with MS from 17 European centres in nine countries. The results: 75% of those involved reported minimal to significant improvement following physical exercises. *"An intensive boost in exercise can have an impact, even in improving walking"*, Peter Feys emphasised.

Finally, Peter Feys said that there are two ways of encouraging people with MS to exercise more: the first one is convincing them that exercise can actually improve their health and the second one is encouraging them to practice within their own community rather than in a secluded environment.

**Peter Feys' detailed presentation is available
at www.emsp.org**

Rehabilitation and the role of carers

EMSP's Anniversary Spring Conference reserved a special place in the programme for carers of people with MS, often marginalised in strategies and policies on multiple sclerosis. Doctor Jacinta Morgan, specialist in Rehabilitation Medicine, and caregiver Elisabeth Golding, the wife and carer of John Golding, offered a comprehensive overview on the role of carers with two different, but complementary presentations.

Dr Jacinta Morgan started her presentation with a definition of rehabilitation: *"A process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function".*

Dr Morgan went on to unfold her personal and professional links with MS: as a carer for her aunt living with multiple sclerosis and also by coming into contact with hundreds of MS patients in her past job as Consultant Physician at the Royal Cornwall Hospital in Ireland.

Jacinta Morgan stressed the role of the multidisciplinary team in the rehabilitation process while underlining that, at present, "rehabilitation services for people with MS are very patchy – my aunt for example relies more on the MS society and loved ones".

Speaking about carers, Jacinta Morgan divided this group into two sub-categories: paid carers and family members – with the following main characteristics:

THE MANY ROLES OF A CARER	
PAID CARERS PAs	FAMILY MEMBERS
Assistance with and/or supervision of: <ul style="list-style-type: none">• personal care• domestic tasks• passive and active exercises• cognitive exercises• household management• community participation: leisure, driving, work	<ul style="list-style-type: none">• physical helper (personal and domestic care)• motivator• health and social advocate• protector• logistician• income and resource gatherer• counsellor and soul mate

Detailed presentations from Elisabeth Golding and Jacinta Morgan are available at www.emsp.org

Dr Jacinta Morgan (left)
Elisabeth Golding (right)



In her conclusion, Dr Jacinta Morgan urged RIMS and EMSP to survey carers and to start defining their role, which she described as “massive and irreplaceable, but not properly documented yet”.

When it was her turn to appear before the Conference audience, caregiver **Elisabeth Golding** from Norway went straight to the root of the many challenges which MS carers have to face:

“I thought right from the start that the role of MS caregiver has been a forgotten one and one of low priority in the MS world. I have realised that there are many caregivers and relatives of people with MS all around the world who feel deep loneliness and a great need to share their plight, their feelings and their thoughts with someone”.

Ms Golding has been caregiver to John Golding for nearly 30 years and, according to her own account, had to give up her academic and professional ambitions in the process. But she managed to find solace in caring for her husband and even a renewed sense of purpose when she started to support other caregivers:

“In 2008, I was so lucky to be asked by the Norwegian MS Society to lead a group of experienced partners of people with MS – we met once every other week and tried to support each other. For many of them it was the first time they could share openly experiences and difficulties as MS caregivers.”

Closing her presentation, Elisabeth Golding sent a strong message to all those living with multiple sclerosis: *“I would like to address all of you who have MS and appeal to you always to appreciate your caregivers, be they family or friends. Caregivers need some free time to be alone and load their batteries. The more understanding you are to caregivers, the easier it becomes for both parties to tackle MS.”*

Well-being marketplace

ACTION LEADING	DESCRIPTION
1 Move to Sport <i>Paul van Asch</i>	Demonstration of exercises with special equipment
2 Sail for MS <i>Mikkel Anthonisen</i>	MS/Sailing Sclerosis campaign
3 Hippotherapy <i>Therese Luscher</i>	Therese Luscher from Swiss MS Society talked about their experience with hippotherapy.
4 Physiotherapy <i>Adeline O'Dowd</i>	
5 Serbian Rehabilitation clinic: Atomic Spa <i>Nevena Jelic and Dr Lidija Obradovic Bursac</i>	Demonstration by therapist.
6 Fitness for people in a wheelchair <i>Lynne Shepherdson</i>	Lynne, a fitness expert and Shana Pezaro's carer, organised a special session of exercises.
7 Fitness for MS <i>Alan Dunne</i>	Complete body fitness for people with multiple sclerosis.
8 Music and the Brain <i>Olga Bobrovinkova</i>	MS advocate and artist Olga Bobrovnikova promoted her book in which she talks about the importance of music in managing MS.
9 Intelligent toilet <i>Attila Rist</i>	A company in Hungary that has developed an adjustable toilet – winning EU project.
10 Rehabilitation at home <i>Belgian Melsbroek Centre</i>	Demonstration of exercises that can be done at home by MS patients.
11 Kinect Xbox: Virtual Rehabilitation <i>Julio Alvarez</i>	Julio Alvarez Guzman, Director of the Health Department at Virtualware, presented VirtualRehab, a technological solution which has led to significant improvements in patients with MS.
12 Bioness	L300 – FootDrop mechanism improving speed and balance in walking
13 Mindfulness <i>Fidelma Farley</i>	Meditation and strategies for living well.
14 Zumba	Special Zumba session, Conference room

Peter Flachenecker
and **Paul van Asch**

EMSP invited two highly respected specialists – German neurologist **Peter Flachenecker** and Belgian physiotherapist **Paul van Asch** – to coordinate the special session involving demonstrations and lessons from a vast array of rehabilitation practices, from physical exercises to health apps, from hippotherapy to sailing.

Under the coordination of Paul van Asch, an impromptu Zumba session was organised in the Conference room, all participants joining in enthusiastically. This moment was remembered by several participants in the post-Conference survey.



Launch of the Young People Programme

In one of the most anticipated moments from Day 1 of the Conference, EMSP Chief Executive Maggie Alexander and Project Coordinator Emma Rogan officially launched the long-term initiative aimed at creating opportunities for young people with MS to access work placements and remain in work – Believe and Achieve.

“Diagnosis and the symptoms of MS in early adulthood can have significant psychological implications. Education, career and life trajectory can all be affected”, said **Maggie Alexander** at the beginning of the presentation. When MS hits, work opportunities can be lost, she added, indicating that this fact was the main incentive behind Believe and Achieve.



Project Coordinator **Emma Rogan** substantiated the opening remarks with results from an EMSP survey among 1,300 young people living with MS in Europe. Nearly 70% of respondents said they are affected by fatigue, while more than 40% claimed cognition problems, both typical MS symptoms.

In order to tackle these issues, Believe and Achieve has set two main goals:

- create work opportunities for young people with MS through partnerships with businesses;
- provide know-how for employers on workplace adaptations for people with MS.

“ Employment is very important because of the recognition I gain and because I am part of the ‘normal’ working community and that makes me feel good.” EMSP Employment Survey 2014

Maggie Alexander (left)
and Emma Rogan (right)



“

We need to be provided with reasonable workplace accommodation – slight adjustment in duties. I am highly qualified which ensures flexibility.” EMSP Employment Survey 2014

EMSP intends to find 10 employers from across Europe who will offer a young person with MS a 6 to 12-months paid internship in a relevant field. Also, EMSP is working to create clear guidelines for workplace adaptations.

That such measures are sorely needed becomes increasingly clear when consulting some of the quotes from the survey.

As Maggie Alexander and Emma Rogan both showed, Believe and Achieve will benefit not only the employees, but also the employers – who are very likely to obtain some or even all of the following: talent acquisition, extended reach in the job market, reputation management, enhancement of equal opportunities work practices, corporate social responsibility and ‘employers of excellence’ status.

Maggie Alexander’s and Emma Rogan’s detailed presentation can be found at www.emsp.org

Therapies and recent developments

After a short introduction from MS Ireland Chief Executive Ava Battles and EMSP Deputy Chief Executive Christoph Thalheim, Day 2 of the Conference kicked-off with a presentation from French neurologist **Oliver Heinzlef**, President of the French MS Society LFSEP.

Dr Olivier Heinzlef structured his presentation in two main parts: results and side-effects of MS drugs, starting with the so-called first line treatments, moving on to the second line and finally speaking about the upcoming drugs.

First line treatments

Results

From Betaferone to Copaxone, the use of these drugs brought a reduction of the relapse rate, an increase of the number of patients without relapse and also an increase in the delay between relapses. The use of Interferone is also considered to reduce the risk of death in patients.

Side-effects

Flu-syndrome, fatigue, cutaneous reactions, hepatic issues.

However, no increased risk of so-called malignancies or severe infections has been identified even after years of exposure

Second line treatments

Dr Olivier Heinzlef talked about three second line treatments:

Natalizumab (Tysabri), **Fingolimod** (Gilenya) and **Mitoxantrone** (Elselp)

Results

Natalizumab – one of the most efficient MS drugs. More than 60% of tested or reporting patients have no more clinical activity under this treatment and nearly 40% of patients are activity-free, no clinical or MRI-activity.

Fingolimod – it could have neuroprotective effect on the brain.

Reduction in the rate of relapse as compared to placebo of about 55%.

Mitoxantrone – improves clinical and MRI-activity. Relapse rate decreased by 90% and patients under treatment have less MRI-activity.

Side-effects

Natalizumab – it has a complex risk-benefit ratio with the occurrence of the progressive multifocal leucoencephalopathy (PML) in 0,2% of patients. PML is a viral infection, a very severe disease and 20% of patients who acquire it risk death or severe disability.

Fingolimod – cardiac side-effects, hepatitis, lymphopenia infection or hypertension.

Mitoxantrone – the use of this drug is limited because of its serious adverse effects: cardiac toxicity and acute leukemia in about 1% of patients.



Upcoming treatments

The neurologist also offered a preview of some of the upcoming treatments. He divided the new drugs and treatments into six big categories:

- non-specific immunosuppression and immunomodulation;
- selective immunosuppression (very basic explanation: immunosuppression and immunomodulation are therapies attempting to dampen down the immune system while limiting the number of side-effects);
- immune cell trafficking;
- neuroprotective drugs;
- remyelinating drugs and cell stem therapy.

Under the first mentioned category, Dr Olivier Henizlef talked, among others, about **Tecfidera** (BG-12) and **Aubagio** (Teriflunomide).

Results

Tecfidera – its exact mechanism of action is not fully understood but studies have shown significant effect on the relapse rate and risk of disability progression.

For example, 70% of patients experience no more clinical activity on the treatment, compared to 50% on placebo.

Aubagio – strong effect on the relapse rate, reduction between 30-36% in some studies.

Side-effects

Tecfidera – flushing, gastro-intestinal issues.

Aubagio – gastro-intestinal side-effects, infections, potential risk on pregnancy.

In the second category, Dr Heinzlef mentioned, among others, **Lemtrada** (Alemtuzumab) and **Ocrelizumab**.

Results

Lemtrada – used in Europe for adult patients with aggressive disease. Strong effect on risk of relapse and sustained disability, reduction of 30% of risk of progression compared to Interferone Beta-1.

Ocrelizumab – strong effect on MRI and relapse-rate. Study in primary progressive MS is ongoing, results in two or three years. Has shown that it could prevent the progression of the disease in young patients.

Side-effects

Lemtrada – Mainly infections and auto-immune diseases. Several patients died during clinical development.

Ocrelizumab – awaiting further studies.

While briefly mentioning the next categories of new drugs, he also stressed that long term strategies to evaluate the safety of new drugs are mandatory.

“

Our therapeutic strategy with these different drugs: we treat patients with first line drugs even after the first relapse if they are considered to be at high risk. One very important point is to identify early the bad responders to treatment – and in this situation we introduce second line treatments like Tysabri and Fingolimod”

Dr Heinzlef

Dr Olivier Henizlef's detailed presentation is available at www.emsp.org.

The role of EMA in ensuring access to high-quality medicine in Europe



The second presentation on Day 2 was delivered by the Head of Patients and Healthcare Professionals Department in the European Medicines Agency (EMA), **Isabelle Moulon**.

With its main role of evaluating the marketing authorisation application for human and veterinary medicine, EMA is always looking at the quality, efficacy and safety of the proposed medicines, said Ms Isabelle Moulon at the start of her presentation.

She continued by outlining some of the challenges EMA is confronted with on a permanent basis:

“ We live in a global society and there is a lot of scrutiny between the different regulatory authorities, especially when there are divergent decisions. Also, patients are requesting, very rightly, early access to medicines and this is risky.”

Regulators – Isabelle Moulon continued – are now looking to bridge the gap between the clinical development of medicines in a very controlled environment and the therapeutic use in an uncontrolled environment. Constant interaction with patients and healthcare professionals is key, she mentioned.

EMA follows the new drugs in three phases: development, evaluation and market.

In the development phase, EMA looks at innovative methods and scientific advice.

For the first step, EMA will support the adoption throughout the MS community (patients, clinical investigators, pharmaceutical industry, regulatory agencies, and advocacy groups) of a clinical outcome assessment tool for future MS clinical trials. This tool will measure the impact of an intervention on the disability due to MS and will be qualified for use in registration trials.

For the second step, EMA enables early development discussions with Regulators and Health Technology Assessment Bodies (HTA), with the possibility to look at new issues in the near future, such as the impact on caregivers.

In the evaluation phase, there are several regulatory pathways facilitating access to markets. A special focus falls on the approval under exceptional circumstances and on the so-called compassionate use, which basically allow new drugs onto the market earlier where there are unmet medical needs or life threatening diseases. In these cases, the decision is made together with patient organisations and medical professionals.

There is also a new method for the evaluation phase, **adaptive licensing**.

“We put the product on the market earlier for a more restrictive population, while the company continues the drug development and at the same time having a very controlled marketing phase, before we get more data to grant the full license”, Isabelle Moulon explained.

Finally, in the market phase, EMA applies tools such as the **pharmacovigilance**, which brings better public participation and with it better evidence, greater transparency and better information. An example offered by Ms Moulon is the “black triangle”, a graphic insert on the leaflet of all the medicines with identified side-effects which need to be further studied. The triangle signals to patients and healthcare professionals that their feedback is expected.

In her conclusion, Ms Isabelle Moulon said that EMA is constantly looking at better ways to interact with all the relevant stakeholders in the drug development process:

“ This is a complex area that may require innovative methodology and this is what we want to look at, to capture all the different needs along the patient journey. We all need to collaborate in order to have high-quality medicine on the market.”

Isabelle Moulon's detailed presentation is available at www.emsp.org

Advancing the cause of MS during the Year of the Brain and World MS Day

The presentations continued with an extremely interesting account on raising awareness of multiple sclerosis on the European and global level offered by representatives of the Multiple Sclerosis International Federation (MSIF), and the European Federation of Neurological Associations (EFNA).

Sophie Paterson (MSIF) spoke about the strategy and deliverables of the World MS Day – a worldwide event initiated by MSIF in 2009 as a way to unite different people from different countries and continents around a common cause, MS.

There are four key messages which shape the communications strategy of each World MS Day, according to **Sophie Paterson**:

- **there is no known cure for MS;**
- **multiple sclerosis is usually diagnosed between the ages of 25 and 31 and lasts a lifetime;**
- **life with MS is very unpredictable because symptoms vary widely from person to person;**
- **treatments and services are improving for people with MS, but not for everyone, everywhere.**

In 2009, the main call to action of World MS Day was for all interested stakeholders to “join the global movement and end MS”. From 2010 to 2013, the global event held on 28 May encouraged all its supporters and partners to campaign around essential topics such as work and employment, living with MS and young people respectively. In 2014, the event was to be focused on the theme of access.

World MS Day's influence is increasingly visible both online and offline, Ms Paterson stressed. As examples, she offered the 65,000 unique web hits which the dedicated website gathered in May 2013 and the successful campaigns run over the past years in countries as different as China, Mexico, Australia, India, Croatia or Morocco.

Audrey Craven (President of EFNA) talked about the increasing importance of branding the brain in an environment where the patient voice can sometimes be “fragmented”.

Audrey Craven said that the 2013 European Month of the Brain went a long way to creating a united front on the area of brain disorders. From the conclusions of the 2013 event Ms Craven said:



“ Consideration should be given to enhancing the engagement of patients in all steps of the research cycle. Patients need to be actively involved in the planning of research approaches, the execution of services and the maintenance of standards of healthcare practice.” Audrey Craven, Presiden of EFNA

And how can patients be actively involved? According to Audrey Craven, through projects around empowerment and capacity building and by linking national and European platforms. Also, and very importantly, through the Year of the Brain initiative (YotB), coordinated by the European Brain Council (EBC) – of which EFNA is a board member.

Sophie Paterson's and Audrey Craven's presentations can be found at www.emsp.org

Driving improved access to treatment via Europe and through national MS societies

Invaluable insight was shared with participants when EMSP's Deputy Chief Executive and Director of External Affairs **Christoph Thalheim** stepped onto the stage to answer one of the key questions on managing MS: "What is the added value of involving patients in the scientific process?"

"In general, patients bring real-life experience of the disease and its current therapeutic environment. As a consequence, patient involvement enriches regulatory outcome by complementing it with the views of those directly affected by regulatory decisions", said Christoph Thalheim.

He added that today's patients are increasingly well-informed and organised, having evolved from being placed at the bottom of the prescriber-regulator-pharmaceutical industry paradigm 10-20 years ago to featuring more and more at its centre nowadays.

Mr Thalheim mentioned that patient representatives have been co-opted as full members of the Management Board of European Union's medicines regulator, the European Medicines Agency (EMA), and are regular participants in the Agency's workshops and conferences.

Another example offered by Christoph Thalheim in proving the patients' increased influence is the Tysabri case: a second line MS drug which was nearly rejected by EMA after two people died of its side effects during clinical trials but which was eventually approved after strong interventions from patients' advocacy groups. This case offered some important conclusions, according to Christoph Thalheim: the safety concerns of medical experts and regulators are not necessarily identical with the benefit-risk assessment of patients and people with MS may accept higher risks than medical experts perceive.

“Patient involvement enriches regulatory outcome by complementing it with the views of those directly affected by regulatory decisions.”

Christoph Thalheim, Deputy CEO of EMSP



In the second part of the presentation, Mr Thalheim was joined by a representative of the Polish MS Society, **Luiza Wieczynska**, in highlighting a potential driver of change in patient involvement – EMSP's MS Barometer.

This collection of comparative MS data gathered by MS societies around Europe and centralised by EMSP was launched in 2008 and reached its fourth edition in 2013. Scoring lowest in MS management among 25 participating states, Poland is a country where many improvements are still required in areas such as access to disease-modifying treatments.

The Polish MS Society is striving to create the right social and political environment through constant outreach to decision-makers and industry and by organising successful awareness-raising events, such as the MS Abylimpics – a series of competitions with the disciplines ranging from decoupage to water colour painting.

Christoph Thalheim's detailed presentation is available at www.emsp.org

The value of non-profit marketing during the economic crisis

Moving towards the end of Day 2, **Savas Kalfas** from the Greek MS Society briefly presented the success story of the Under Pressure “marathon” organised in Greece between October 2013 and March 2014.

Savas Kalfas informed the audience that the 38 photo panels depicting stories of people living with multiple sclerosis in countries as diverse as Iceland and Belarus were exhibited in four different venues from Athens and Thessaloniki: Aristotle University of Thessaloniki (15-17 October), City Hall of Thessaloniki (5-24 January), Cultural Center of the Municipal Building of Panorama (25 January – 5 March) and the American College of Greece, Athens (7-22 March).

The Under Pressure exhibitions drew a total crowd of over 1,000 people, from local authorities and specialists in the field, to representatives of the pharmaceutical industry and art students, according to Mr Kalfas.



A full report of the Under Pressure Greek exhibitions is available in the News Section of EMSP's Under Pressure project at www.underpressureproject.eu



The visual impact of the Conference setting was enhanced by the new Under Pressure exhibition set (pictured above)– with a leaner format and featuring different but no less impressive photo panels, in comparison with the two older exhibition sets.

Launch of Defeating MS Together, the Code of Good Practice in MS

In another widely anticipated moment from EMSP's Anniversary Spring Conference, Doctor Alexis Willett and Professor Gavin Giovannoni jointly introduced the newly revised version of the European Code of Good Practice in MS, *Defeating MS Together*. The Code was originally published in 2005 to highlight issues faced by people with MS and the measures needed to drive improvements.

"We really want to make sure the document is aimed at policy-makers. It has action-focused language and there are also quotes in there to give people a real sense of what life is like for people with MS and their carers. It incorporates 12 calls to action that we want to see improvements being made on", said in her introduction Alexis Willett, the author of the revised Code of Good Practice in MS.

There is one core principle which runs throughout the document – the empowerment of people with MS.

"People with MS and their carers have to be involved in decision-making about their treatment and care, and also to feed into research and policy – which ultimately affect them", said Dr Willett.

Alexis Willett also stressed that the revised Code is meant to be *"an active, living tool that you refer to, and disseminate, regularly"*.

At the end of her short speech, Dr Willett encouraged all stakeholders, using the wording from the Code, to *"commit, support, advocate and act – if we are going to make progress."*



Defeating MS Together
**The European Code of
Good Practice in MS**

Alexis Willett (left)
Gavin Giovannoni (right)



Picking up where Dr Willett had left off, renowned **Prof Gavin Giovannoni** said that the Code gives the MS community and stakeholders a common purpose. He also emphasised that *“very few of us in this field view MS in a realistic way and that needs to change.”*

“It is very important for us to have this Code because it is pretty shocking that there is still such a wide variation of access to treatment for people living with MS in Europe”, added Prof Giovannoni.

The Professor also had a special message to convey: that the Code needs the backing of more neurologists.

“I would really like to encourage you to start an education programme not only for nurses, but for neurologists as well. It is essential that we also train the neurologists”, explained Prof Giovannoni.

Both the Code and the joint presentation were especially well received by the audience.

The detailed presentations by Alexis Willett and Gavin Giovannoni, as well as the pdf version of the revised Good of Good Practice in MS, can be found at www.emsp.org.

Launch of the Under Pressure Irish Video

Another exciting feature before the official closing of the Conference was the launch of the Under Pressure video for Ireland. As an ex-Chief Executive of MS Ireland, EMSP's then Vice President (current President) **Anne Winslow** presented the video.



Anne Winslow started by reminding the participants that the Under Pressure project is part of EMSP's commitment to address health policy needs and inequalities in Europe. She added that the project emphasises the sharp differences in access to treatment, care and employment for people living with MS in Europe through a collection of short documentaries and impressive photos, and three exhibition sets. The project's wide reach stems from the fact that the team of five accomplished photographers visited several people with MS in 12 European countries.

“The sharing of stories has helped people feel less isolated and also maybe better understood. Also, MS societies and neurologists working with this project said that it reminds them what we're all about”

Anne Winslow, current President of EMSP

Ms Winslow went on to say that the Under Pressure video for Ireland tackles many aspects of living with multiple sclerosis in a country which has one of the highest prevalence rates in Europe – 140 per 100,000 people. She also acknowledged that the film addresses several other areas of MS management in Ireland which can and should be improved: the neurologist per patient ratio and access to employment.

This part of the Conference was made extremely special by the arrival of one of the people with MS featured in the video, **Mary Bartley** (pictured below). Joined by her husband and son, Ms Bartley was delighted with the reception the video received and expressed her willingness to continue supporting the Under Pressure project.



www.underpressureproject.eu

Celebration of EMSP's 25th Anniversary

After introducing the Conference, it was only fitting that EMSP's outgoing President John Golding would also close the event. He chose to do so with a brief summary of EMSP's history. His presentation was bolstered by short addresses from past EMSP President Mario Battaglia and the Chairman of MS Ireland's Board, Manfred Huschka.

John Golding started by mentioning EMSP's founding members: Princess de Merode (Belgium), Manuel Creyns (Spain), Udo Kruse (Portugal), Monique Crenesse (France), Professor René Marteau (France), Hans Arne Melbye (Norway) and William Lonergan (Ireland).

EMSP initially had 21 member societies and its first President was Alberto Saenz from Spain. Succeeding Presidents included: Miriam Geneset (1994-1997), Mario Battaglia from Italy (1997-2000), Michael Willis from the UK (2000-2002), Peter Kaufeldt from Denmark (2002-2006); Dorothea Pitschnau-Michel from Germany (2006-2010) and John Golding (2010-2014).

John Golding also emphasised a number of key achievements from EMSP's 25 year history:

- **the first Awareness Day in the EU Parliament followed by the first EU funded project in 2002;**
- **the creation of the European Map of MS with MSIF (to become Atlas of MS) in 2004;**
- **first MS Barometer survey took place in 2008;**
- **MS Information Days organised yearly in the EU Parliament between 2011 and 2013;**
- **written Declaration on Multiple Sclerosis passed by the EU Parliament in 2012.**

In 2014 – said outgoing President John Golding – EMSP can rely on the support of a network of 39 MS societies and 16 industry partners.



“

EMSP acts as an interface between its national members and European bodies and we can safely say that we are initiators and leaders of innovative MS related projects at European level.”

John Golding

John Golding's presentation on the history of EMSP can be found at www.emsp.org.



Anne Winslow was elected as President of EMSP following the Anniversary Spring Conference



Parallel Session 1

Carers' Concerns

In one of the most interactive parallel sessions from Day 1 of the Conference, MS carers Gemma Donnelly and Elisabeth Golding shared their insight into living with a partner who has multiple sclerosis and invited the audience to ask questions and give their own accounts.

Elisabeth Golding, MS carer for nearly 30 years, started by saying that, unlike the situation in other European countries, being a carer in Norway, where she and her husband John Golding live, is not a question of money.

“So what is the problem? I gave up my career to care for my husband – not something admired in my country because everybody is expected to be working full-time. It can be very lonely as a carer”, Elisabeth Golding explained.

She coordinates a group of carers, who meet regularly to discuss and consult on important matters from their daily lives.

One piece of advice that Elisabeth Golding offered the carers present at the parallel session: *“The person with MS has to be treated with respect, not with pity.”*

On her part, **Gemma Donnelly**, who prefers to consider herself more a partner than a carer for her husband living with primary progressive MS, made a few observations from her own experience:

“It’s a story in which we balance caring and love. It is also an issue of identity: I am caring 45 hours per week for my husband but my identity is not as carer, I’m not particularly good at it. Well-being is really important in our lives. Also very important is to be a part of a group of carers. I joined an online group, almost 70 percent of the members have a relative with MS – the thing that keeps me strong is the network”.

The openness and honesty shown by the two moderators encouraged those present to express their own feelings without restriction, as shown by the quotes highlighted on the next page.

The discussions also touched upon other sensitive topics for the carer-patient relationship, such as the feelings of guilt a carer may experience when being away from his or her partner with MS or the shame that children of parents with MS may feel when they have to approach the topic with other youths of similar age.

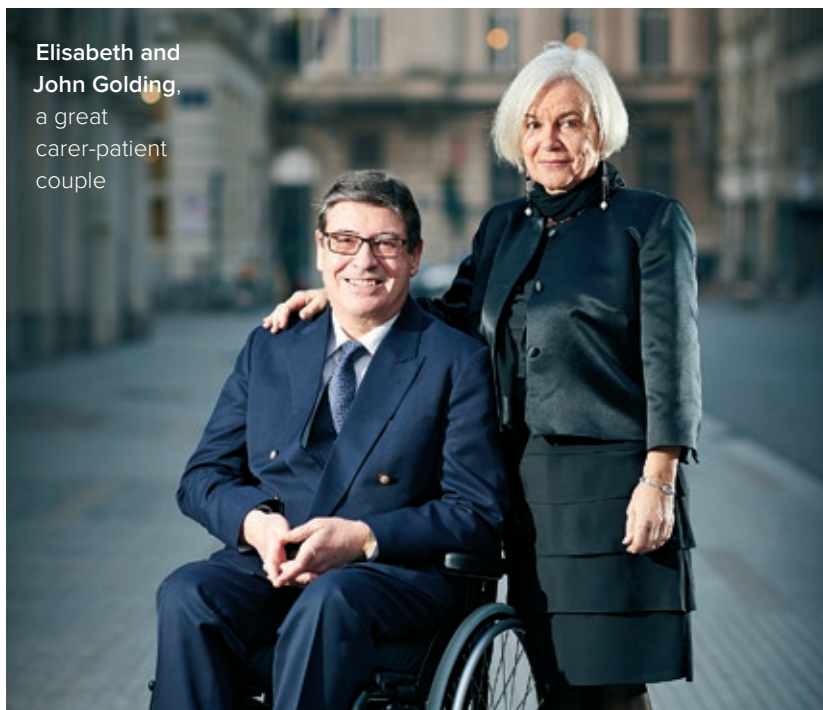
Although there were many needs identified during this parallel session, one appeared to be the most obvious and pressing: because of the fluctuating and unpredictable nature of the disease, the support that caregivers receive is essential for their own well-being.

“

I am very angry, I feel we carers are forgotten about in Ireland. Sometimes you break down, you feel that when asking for more support you are just begging, begging, begging.”

Brida O’Gorman (Ireland) – has a daughter with MS

Elisabeth and
John Golding,
a great
carer-patient
couple



“

MS patients should have more carers available. A big problem is the lack of carers at night.”

Yaroslava (Slovakia)

Parallel Session 2

Young People's Focus

This session was focused on the experiences of people diagnosed with MS at a formative stage in their lives. Main topics discussed: living well with MS, coping strategies and the issues of dealing with psychological effects as well as life in general.

Before engaging in what were very lively and constructive debates, three people living with MS briefly told their stories.

Shana Pezaro

She is an MS advocate living in Brighthon, UK and the newly elected Young People's Representative in the EMSP Executive Committee. She spoke about maintaining her identity.

"I can't run marathons but I can, and do, exercise at the MS treatment centre. I am unable to work but I do voluntary work, which gives me a sense of identity and self-worth."

"My body might fail me in many ways. But that doesn't mean it is the end of my life, of my identity, or my fun."

“

Helping people to come to terms with the diagnosis and live their lives to the fullest is an absolutely essential part of treating someone with MS. It's really not just about medication and physical treatment. It's also about mental health and well-being.”



George Pepper

He is an MS advocate from Leeds, England. He is co-founder of Shift.ms, a social network for people diagnosed with MS – a positive, empowering community. He spoke about maintaining good mental health.

“The forced change of perspective and circumstances following the MS diagnosis created in me a desire to react, a compulsion to do something positive, to ensure MS was not the main focus in my life.”

“The outlets for harnessing your MS energy might be: focusing or re-evaluating your work and career, prioritising meaningful relationships with family and friends, meeting someone new, deciding to start your own family. “

“

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

Scott Ahearn

He is Outreach and Partnership Officer with SeeChange, Ireland’s national mental health and stigma reduction partnership. He spoke about positive change in public attitudes and behaviour on mental health issues.

“Some strategies used by SeeChange include the Town Hall meetings, events held in cooperation with local community networks with the aim to start conversations about mental health at local and community level.”

“The one thing that is common across all countries and cultures is the stigma around talking about mental health difficulties.”

The second part of this parallel session allowed moderators and participants to identify and offer solutions for some of the recurrent challenges posed by MS. **Three problems were named: isolation, stigma and mental health.**

For isolation, the solutions referred to workshops and information days to spread knowledge and expertise, possible phone lines connecting people with MS to healthcare professionals, physical exercise and diet.

For stigma, the solutions recognised the use of social media as a driver for change in attitudes, the visual arts as a way to ease hurt and open up discussions and story-telling as means of encouragement.

For mental health, the solutions identified funding for counselling, self-management courses and empowering people to take control of their health.

As a conclusion for the parallel session, MS advocate Emma Rogan said that *“we want to encourage all young people with MS to learn what they can do to transform their own minds, how to share the learning with other young people with MS and wider society, and how be part of the action to bring about change in their own regions”.*

Parallel Session 3

MS Nurse Pro in Ireland

Moderators Aidan Larkin, Anne Winslow

Rapporteur Willeke van Eeckhoutte

This parallel session presented a new way for MS nurses across Europe to start or enhance their MS education in any setting, using five key modules of online learning. This is possible through EMSP's MS Nurse PROfessional project.

The moderators of this parallel session, Aidan Larkin from MS Ireland and Anne Winslow from EMSP showed that topics such as understanding MS, clinical presentation, diagnosis and assessment, treatment, care and support all show current ways of dealing with patients and how to find the key link between neurologist and patient.

With over 700,000 people living with MS in Europe, treatment is diverse and often hard to manage. This is why MS nurses are essential for assessing symptoms and targeting treatments. They also help in adhering to medication schedules.

"In the ever-changing field of new research data, it is important that nurses can keep developing and improving their knowledge across a wide range of needs and wishes from patients as well as others involved in MS care", said Anne Winslow.

MS Nurse PROfessional went live in Ireland in November 2013 and already proved its value in how it fitted in the variety of care MS patients may require during their lifetime. The program is now active in the Czech Republic, Germany, Italy, Spain and the UK as well as Ireland.

More details about MS Nurse Pro are available at www.ms nursepro.org



Parallel Session 4

Exchange of Good Practice

This parallel session had the advantage of reuniting the experience of healthcare professionals working in different EU countries. Tom Meurrens and Stephan Ilsbroux represented the National MS Center in Melsbroek, Belgium. Mariusz Kowalewski and Malgorzata Stachowiak were present on behalf of the 'John Paul II' Rehabilitation Center in Borno Sulinowo, Poland.

Dr Stephan Ilsbroux and **Tom Meurrens** had the first presentation. Their centre last year admitted around 800 MS patients. According to Dr Ilsbroux, once at the centre a person with MS can receive recommendations to follow one of the listed programmes: **Early Guidance, In-Patient Rehabilitation, Out-Patient** and **Continued Care**.

Early Guidance, for example, runs over three weeks, with 2 ½ days per week of conveying and receiving information while engaging in different therapies, such as physical, occupational, speech and psychological.



Tom Meurrens, Medical Director of the National MS Center in Melsbroek, Belgium

CONTINUED CARE PROGRAMME

- **Program for patients with MS or ALS in an advanced stage of the disease**
- Convention with Belgian National Health Insurance since April 1, 2009
- **Goal: to provide adequate residential living conditions, whereby people with MS can receive the necessary surveillance and multidisciplinary care adapted to the evolution of the disease**

In Continued Care, the focus falls on giving extra care and supporting families, as described in the slide inserted above.

Dr Mariusz Kowalewski and **Malgorzata Stachowiak** followed. Dr Kowalewski mentioned that at present the Borno Sulinowo Center can admit only 15 patients at a time for a 3 weeks rehabilitation session. He added that demand is so high that those interested may sometimes have to wait between 12 and 18 months for their turn. He also mentioned that the Polish centre he represents gained a lot of inspiration for the services it provides from its continued cooperation with the Melsbroek Center in Belgium.

Dr Kowalewski also announced the intention to create an Institute at national level to continue and enhance the rehabilitation programme started by the 'John Paul II' centre.

Malgorzata Stachowiak stepped in to explain what the intended Institute would have to offer. Ms Stachowiak said that while nothing can replace the personal contact between healthcare professional and patient, the new Institute would be employing IT services which can assist those affected by MS. One of them is called tele-rehabilitation and *"it would provide constant supervisory control as well as intervention when it is needed"*.

The Institute would use other IT tools such as e-education and a data base with digital information about the patients. These ideas would be implemented through broadband internet, video-chat platforms, 2D and 3D cameras for exercises, and e-libraries.

Parallel Session 5 – Reducing social isolation of people with MS

Attracting great interest from the many people with MS present at EMSP's Anniversary Spring Conference, this parallel session was conducted by two people with special insight in addressing the problems raised by this disease.

Haley Sanner is a junior at the Davidson College in North Carolina (USA) where she has conducted independent research on strategies and approaches to mitigating social isolation in aging and MS communities – from both the US and abroad. **Freddie Yauner** is an artist and social entrepreneur who co-founded the award winning social network [shit.ms](#) for people with multiple sclerosis. Haley Sanner started her speech by raising an important question: *"How do you allow someone to stay included?"*

The answers gravitated around the concept of care. A 'network of care' and 'multiple layers of care' were the solutions found by participants. *"The key is to understand the identity of the individuals we want to shelter from social isolation. This identity may not always match with that of the MS society"*, said Ms Sanner in her conclusion.

Freddie Yauner talked about simple but effective actions: engaging conversations and discussions and exchanging information. *"The trick here of course is to find like-minded people, with the same age and same interests"*, said Mr Yauner.

Positive thinking was identified as a way in finding like-minded people. Saying *"I'm a cyclist and I have MS rather than I have MS and I'm a cyclist"*, for example.

By the end of the parallel session, the moderators were able to gather a number of useful suggestions for integration of people with MS. Among them:

- **develop accessibility in terms of travel, physical exercise and access to internet;**
- **build maps to show where the accessible places are;**
- **younger people with MS to teach older ones how to use internet;**
- **crowdsourcing is a solution to be developed further;**
- **online mind games to support cognitive impairments.**



“

They key is to understand the identity of the individuals we want to shelter from social isolation. This identity may not always match with that of the MS society.”

Haley Sanner

Parallel Session 6

Mobile MS evaluation unit in Greece

Moderators **Makis Oikonomou and Dr Vasiliki Garopoulou**

Rapporteur Aoife Kirwan

Makis Oikonomou and Dr. Vasiliki S. Gavopoulou conducted a presentation on mobile MS evaluation units. The cross-border programme was co-funded by the Greek MS society and the Open University of Cyprus. The aim of the project: *“to help people with MS, their relatives and the general population to benefit from the development of a cross-border network that will promote strategies and implement action for the reliable information of the public regarding MS issues”*.

The areas of intervention were the islands of Crete and Cyprus.

“Our mobile unit covered the entire Cretan Island. We drove our mobile unit to every single hospital and medical centre”, said Mr Oikonomou.

The mobile diagnostic units provided free examinations for MS as well as informing public health teams. The personnel involved were three neurologists, three psychologists and two social workers.

Few people visited the unit in the beginning because, as **Mr Oikonomou** stated, *“in Greece, there is a very big stigma for diseases like MS”*. But the campaign did pick up when the Greek media started to promote it. After attending, people were asked to evaluate the unit. Over 60% of participants at this survey agreed that the medical and psychological treatment they were given was better than they had expected.

Over a period of four months, the unit deployed in the Cretan Island covered almost 1,800 kilometers and registered nearly 900 operating hours while visiting five hospitals and 17 healthcare centres.

On her part, **Dr. Vasiliki Garopoulou** said that the project was “a low cost care service in economic crisis, expanding past geographical boundaries.” She added that she personally urged the patients involved not to rush to make decisions regarding their own healthcare.

As her conclusion, Dr. Garopoulou highlighted the importance of “being active in looking at how MS affects you and how you affect your MS”.

The presentation was closed with Mr. Oikonomou’s mobilising words: *“Everything is possible, we have shown that nothing is impossible”*.

Conclusions

“This was the best EMSP conference I have ever attended”, wrote one of the participants in the post-Conference survey the EMSP Secretariat sent out the week after our Dublin event. More than 30 participants completed our survey and we also received significant feedback even outside this formal invitation. All comments and reactions were overwhelmingly positive. Here are a few more examples:

“ I think the timing of the sessions was really good, the mix of presentations, breaks, interactive sessions and fun things like Zumba worked really well.”

“ The present-day problems were discussed at the conference, and everything was strictly kept within the time-limit, which is also important.”

“ Positive, vibrant atmosphere.
Very interesting topics.”

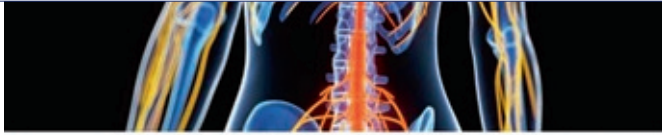
The very positive outcome of the Conference was a fair reflection of the extensive preparations that the EMSP Secretariat, together with event partners MS Ireland undertook.

Some of the highlights of the 'Road to Dublin' included high profile coverage in national Irish media, which was made possible by MS advocate and EMSP Project Coordinator Emma Rogan. On the first day of the Conference she made an appearance on the Morning Edition of the national broadcaster RTE, where she introduced the theme of the Conference. This came after she had spurred interest in the national print media, with the Irish Times publishing a preview article of the Conference (as shown in the insert on the next page).

The social media coverage of the Conference was also a big improvement compared to previous years. For example, the special hashtag created for the event, #EMSP25, was widely used on Twitter (as shown in the inserts below and on the next page).

In terms of trademark publications, EMSP was able to present at its Anniversary Conference a refreshed visual identity, engrained on every relevant document from presentations to our revised European Code of Good Practice in MS.





Studies have shown that early diagnosis allows people with MS to remain in the workplace. Photograph: Thinkstock

Ronan McGreevy

Topics: [Life & Style](#) [Health & Family](#) [Emma Rogan](#)
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Tue, May 6, 2014, 01:00

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Ireland ranks 33rd in the developed world in terms of the provision of neurologists, and this amounts to a false economy, a conference will hear this week.

Late diagnosis of multiple sclerosis (MS), which affects 8,000 people in Ireland, costs the State much more than would be the case if Ireland had more neurologists, according to the European MS Platform (EMSP), which will hold its annual meeting in Dublin on Thursday and Friday. Some 200 delegates and medical professionals from across Europe will participate.

Retweeted by European MS Platform



MS Ireland @MSIRELAND · May 8

Anne Winslow providing valuable information on the [#MS Nurse Professional course](#) and the need for it [@eumsplatform](#) conference [#EMSP25](#)



1

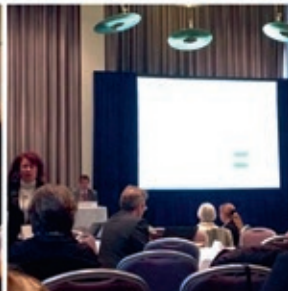


Retweeted by European MS Platform



Aoife Kirwan @aoifemkirwan · May 8

A Zumba session for us lucky people at the [@eumsplatform](#) spring conference [@MSIRELAND](#) [#EMSP25](#) [pic.twitter.com/ROfv49aW3w](#)



1

[View more photos and videos](#)

EMSP did not neglect the 'sound' of the Conference either. The special Gala Dinner organised on Day 1 offered the participants a vibrant musical programme featuring the local Irish House Party and the London-based Take Twenty bands.

The smooth running of the Conference would have not been possible without the great support of the onsite MS Ireland team – with Chief Executive Ava Battles, Communications Office Miriam Taber and bloggers Aoife Kirwan and Willeke van Eeckhoutte among those who were extremely helpful throughout.

During and especially following the Conference, the EMSP Secretariat received a wealth of useful suggestions which we will be looking to implement for our next annual gathering, scheduled for 14-16 May 2015, in Warsaw, Poland. We look forward to seeing you all next year!

“

We are at a stage in the development of MS which is a very promising stage. There is great expectancy. My message to the MS community is let's pull together and find a solution that is needed by all of us. I believe this is possible and achievable – MS is a challenge but it can be overcome.” John Golding

“25 years is fantastic and I've seen such a huge difference over the five years that I've been involved since the EMSP developed a youth programme for the first time” Shana Pezaro

“I have a lot of respect for MS, I have had a lot of interaction with EMSP over the past years. This is an organisation which really stands out as a European voice of the people with MS via MS societies.” Peter Feys

“Sharing experience and knowledge with all the different stakeholders is fundamental in order to understand the disease, the treatment, the needs of the patients, carers and healthcare professionals.” Isabelle Moulon

The Take Twenty and Irish House Party bands



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This report was compiled by
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This report has been designed with reference to best practice guidelines of visual accessibility. We welcome your feedback on the contents and design and suggestions for ways of making our publications more useful and accessible.

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