

## *A word from the Ed*

I'm starting this issue with an apology for the delay in finalising what should have been the final issue of 2009. We are now back on track and you can look forward to receiving future issues of the Bulletin on a regular basis.

Until next time....

Sandy

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## *Highlights from the European Multiple Sclerosis Platform, Reykjavik 2008*

Marijke Duportail (Belgium) talked about creating user-friendly homes by using technology so that everything is controlled by a single instrument, similar to the TV telepilot. In view of the expense involved, this can be introduced in just one or two rooms, instead of all rooms; new rooms can also be added as an extension (forming a "kangaroo home").

Other options are simpler, yet useful adjustments like installing sliding doors and passing on second-hand equipment like electric-wheelchairs to



From Left: Alistair Farrugia, President Olaf Gunnar Grimmsson and Joseph Tabone

people who need them.

Dr. Peter Anderberg ([www.IndependentLiving.org](http://www.IndependentLiving.org)) explained that everyone uses personal assistance (e.g. to repair the car), but people with disabili-

ties need it more. We may also be pressured to make many adaptations that we neither need nor want, and advised: "Don't spend too much time and energy being 'a good invalid'."

In 1984-1989

Sweden developed a system whereby 15,000 people receive an average €100,000 annually to employ personal assistants. Anderberg said that besides being more expensive, group homes encourage

dependence.

Prof.s Heli Valokivi, Thomas Henze and Alan Thompson spoke about available treatments for spasticity and pain. Prof. Thompson insisted that pain can and should be managed, and if necessary we should see an anesthesiologist or pain specialist, rather than tolerate high levels of pain.

Treatments for bladder problems include toilet training, physio, pelvic floor training, and electrostimulation.

Affecting people for 30 – 50 years, with 50-80% being unemployed within 10 years of diagnosis, MS has a major impact. iMS has a major impact because it affects people for 30 – 50 years. Within 10 years of diagnosis, 50% - 80% are unemployed. Multidisciplinary treatment for MS is less costly, because it avoids hospitalisation. It does not reduce the symptoms, but improves quality of life.

Prof. David Bates said

that MS medicines are now more widespread, with Tysabri and Novantrone introduced recently. Fingolimod is effective but has important side effects, while Teriflunomide may be safer. Stem cells and anti-inflammatory drugs may help to allow some natural remyelination.

Bone marrow self-transplant has a 12% risk of death, and does not even stop all demyelination.

There have been 429 US clinical trials for various MS medicines listed at [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov); thousands of people may be in trials right now, but there are still no promising medicines for progressive MS. There is little research on the causes of MS, and no improvement in predicting the long-term course of the disease.

### Workshops

A “Mainstreaming Disability” workshop concluded that provi-

sions for disabilities should be integrated into business and government, not just added on as an afterthought. The goal is to allow people with disabilities to use all schools, shops, buildings, etc.

At a workshop on MS nurses we learnt that in Germany, nurses need 5 years experience before they can get specialised certification; while in Eastern Europe there are usually no MS nurses, and in other countries there is controversy about physios and social workers being trained as “MS nurses”.

We would like to thank the MS Society committee (especially Louise Gusman), the European MS Platform (Dorothea Pitschnau-Michel), Air Malta and Farsons Cisk Ltd., for all the effort and help that made it possible for Joe Tabone and myself to attend the conference.

Alastair Farrugia

### ***Daniela Abela was diagnosed with MS in her teens. This is her story:***

“I was still in my teens when I started experiencing fatigue and difficulty in walking. After several tests with no specific result I went abroad for an MRI as it wasn’t available in Malta at the time. On August 9th,

1995 I was diagnosed with Multiple Sclerosis (MS). It was a nightmare. I stopped living. For some time I only existed. Within a few years I lost the ability to walk, eat, drink and write on my own. I became totally dependent on my family. The only thing that I didn’t give

up was my job which thank God I still hold.

At first I used to cry a lot and pity myself but a close friend of mine helped me to pray and confide in the Lord and I started coming to terms with my situation. During a routine hospital visit, Dr

Galea Debono suggested that I could benefit from physiotherapy at NRU Boffa Hospital and after much thought I decided to give it a try. I stayed there for three weeks, during which time I did a lot of therapy which was exhausting but well worth the effort as I started to gain some mobility in my hands.

I still attend Boffa Hospital for occupational therapy twice a month. With the help of the occupational therapist and a lot

of hard work, I have regained the skills of writing, eating and drinking on my own again. Now I use a motorised wheelchair and am more independent.

Presently my greatest hope is that a cure will be found or at least that there could be a drug that reduces the damage wreaked on my nervous system, As I would be thrilled if I could even just get out of bed on my own and walk a few steps.

I know this may take a

long time to happen so I try to do the best I can to accept my present condition and still go out with my friends and family, enjoying my life.

Daniela

### ***Mr Noel Gusman and Mr Carmel Grech attended the European Multiple Sclerosis Platform Conference in Brussels between 13th and 15th May 2009.***

MS-ID is about information on MS and the benefit to be reaped from it.

At present in Europe there is very little data gathered about MS, its incidence, who is affected by it, who is taking what drugs as treatment, how MS impacts on the lives of people who are diagnosed, what it results in for their participation in the labour market, what additional supports does the State provide and need to provide for people with MS. In order to better understand the impact of MS, we have to know the effects it brings to society at large.

Extracts from the introduction by the President of the EMSP Dorothea Pitschnau-Michel.

- “We developed a tool box to assist our members in their effort to promote and to establish the European Code of Good Practice and its related Consensus papers in their countries”.

- “For the same purpose we designed and implemented National High Level Roundtables, bringing together National Health policy-makers and administrators and the MS society to discuss ways of improving the situation for PwMS (People with Multiple Sclerosis). Four countries so far have used the Roundtable concept quite successfully”.

- “The MS Barometer is our benchmarking tool which

allows the comparison of existing healthcare policies and to point to the unacceptable inequalities in access to healthcare for PwMS in Europe”.

- “The CODE was translated into 14 languages so far”.

- “EMSP is proud to see its CODE and European Consensus Papers being published by the European Commission on its EU Health Portal”.

- “Finally the European MS Register, which has been tested in 5 European countries with completely different health systems”.

**MS-ID Project**

**OBJECTIVES:**

- raised awareness across the EU on multiple sclerosis (MS) enabling stakeholders both at European level and in the Member States to better understand the condition and share information on: the positive impact of early diagnosis couple with high quality treatments, choice of therapies, sufficient social support, and the benefits of good MS management.

- identification and addressing of the major inequalities of MS treatment and care across the European Union and within the EU Member States through the development of new and effective strategies and indicators to measure performance. These will enhance the quality, comparability, applicability and transfer of both statistical and factual data as well as qualitative information on MS across EU Member States.

- use of high quality comparable data at EU and trans-national levels to positively impact on EU / national policy and programmes towards MS and to ultimately empower EU citizens directly and indirectly affected by MS. In short, an improved, better managed and more

equitable approach to the treatment of MS in Europe enabling people with MS to contribute and participate rightfully as full and equal citizens in society.

**PROJECT PARTNERS:**

THE six national MS societies participating in MS-ID project are:

- Deutsche Multiple Sklerose Gesellschaft, Bundesverband e.V., Germany

- MS Society of Iceland, Iceland

- Polskie Towarzystwo Stwardnienia Rozsianego, Poland

- Societatea de Scleroza Multipla Din Romania, Romania

- Federacion Espanola para la Lucha contra la Esclerosis Multiple, Spain

- Multiple Sclerosis Society of Great Britain and Northern Ireland, United Kingdom

**EXPECTED OUTCOMES:**

- create a model of a standardised data collection and management system of different national care approaches to MS; provide a critical evaluation of existing MS data collection methodologies across Europe;

- develop and pilot a standardised European approach to analyse and

compare MS data in the format of a proposed European MS register;

- promote a European code of good practice focusing on quality of life, human capital and social supports linked to MS.

*Who is involved in this Project?*

**EMSP** - The MS-ID project is an initiative of the Multiple Sclerosis Platform (EMSP), a network of 33 national MS societies. The project is piloted by 6 societies, but the project directly impacts also on the wider EMSP membership. Development within, information about and the tangible results of the MS-ID project are communicated to EMSP members on a regular basis

**The Steering Group** (SG) consists of national coordinators from each of the national MS societies implementing the MS-ID project in their organisation. Their role and duties are described in the SG terms of reference document that was drafted at the beginning of the project.

**The Scientific Advisory Committee** (SAC) comprises of a diverse range of professionals with expertise in medical, economic, research, social policy and management of MS care services.

The role of the SAC is to oversee the scientific aspects of the MS-ID project.

To learn of their role in detail, please consult the SAC terms of reference that was drafted and agreed by the SAC in May 2007.

### **Code of Good Practice**

The endorsement of the Code of Good Practice by all national authorities will ensure that the management of care and the delivery of services to people with MS will be of the optimal quality necessary, thereby ensuring an increase in the quality of life of people with MS throughout Europe.

EMSP, to assist its members in seeking the endorsement of the Code, has devised a communications toolkit. The content of the toolkit is listed below.

We hope that this toolkit will be a valuable resource to all EMSP members in their lobbying campaign for the formal recognition of the Code of Good Practice at national level.

### **European MS Register**

Currently, there is no trans-national predominant single program for documentation of MS nor is there an EU-wide MS registry.

The MS-ID project seeks:

- To critically evaluate current data collection methods of MS management across the European Union.

- To develop and test a pilot data collection system (MS registry) for trans-national data analysis and comparison, which could form a basis for an EU wide approach to analyse and compare MS data.

The aim of this project is to identify and evaluate the different key data collection methods and databases that are in use throughout Europe. This will be done by literature search, a European-wide survey, and by means of a conference (MS-ID Conference, May 2007) inviting the European experts in this field.

Based on the evaluation of existing data collection methodologies, MS databases and MS registries across Europe, and the results of the literature search, a pilot data collection system for trans-national data analysis and comparison will be developed and tested.

Foreseen countries for the pilot study are Germany, Iceland, Poland, Romania, Spain and the UK. These geographically, economically and culturally diverse countries were chosen based on strong discrepancies regarding key

areas that are critical for persons with MS, their families and carers, such as (1) disease modifying therapies, (2) symptomatic treatments, (3) rehabilitation, and (4) principles of quality of life.

The establishment of a trans-national data collection system in countries with extremely different conditions will do both, setting a good example for the feasibility of such a project and contributing to the identification of major inequalities between EU countries.

### **The MS Barometer 2008**

The Barometer is a benchmarking tool. It allows us to make appropriate comparisons. Such an instrument enables the entire MS community to identify what aspects of the disease are well-managed in which countries and in what areas administrations need to improve their policies and practices.

The Barometer starts to show how MS is managed throughout Europe, with time the tool will further evolve in reflecting the developments expected in national policies.

More information at [www.ms-id.org/barometer2008](http://www.ms-id.org/barometer2008)

**LAST YEAR'S EVENT****High Level****National Roundtables**

European Parliament Resolution on Petition 842/2001 the effects of discriminatory treatment afforded to persons with multiple sclerosis within the European Union was adopted in the last plenary session of 2003 (also the European Year of People with Disabilities), marking a considerable milestone in the bid to raise awareness of Multiple Sclerosis and its impact on people's lives. The Code of Good Practice – requested by the European Parliament within this Resolution - was subsequently launched in 2007 amid a very positive level of publicity, further increasing awareness. However, despite the organisation of series of National Roundtables for discussion of the issues above mentioned, the first one being organised as pilot project during the EU Presidency of Slovenia. Such an event has the potential to enable a high-level discussion among influential people in relevant fields in Slovenia, prompting a greater level of awareness among them and serving as catalyst to take

further action.

In 2008, National Roundtables were held in three countries:

- Slovenia, May 2008
- Hungary, September 2008
- Bulgaria, November 2008

**• EP Written Declaration:**

A written declaration been circulated in the European Parliament seeking for the extension of the 2003 Resolution (as a result of Louise McVay's petition in 2001) to the 12 EU member states to have joined the EU since 1st May 2004. A petition was submitted to the Petition's Committee to revitalise the written declaration tool as a means of effective change.

The declaration gained 315 supporters. Although the numbers of signatures required (two third) was not achieved, this process was extremely important in raising awareness in the European Parliament with regard to MS and the situation for people with MS in the new Member States

**• EMSP MS Information Day, 13 November, 2008**

The focus of the Information Day held by EMSP in the European Parliament was to provide an update on the latest

research developments in MS as well the MS-ID project, the EMSP driven, EU funded three year study to highlight the differences in the management of MS across Europe. Presentations were made by members of the EMSP, the European Parliament as well as leading neurologists.

This event gives an opportunity to present the MS Barometer. The Barometer is a benchmarking tool which compares how different European countries manage MS. IT allows the entire MS community to identify what aspects of the disease are well-managed in which countries and in what areas administrations need to improve their policies and practices. The MS Barometer is a series of questions with scores allocated according to the answer given. The aim is to have the most points awarded as recognition of the effectiveness of policies in place optimising the situation for PwMS.

**OTHER INFORMATION.****European Map of MS**

The European Map of MS is the European part of the worldwide data base on epidemiology of MS and on resources available to PwMS

*An Explanatory Note on a EU Code of Good Practice regarding the equal treatment of EU Citizens affected by Multiple*

The adoption of a rights-based approach to people affected by multiple sclerosis, including the core issue of equal access to drugs and therapies throughout the European Union is a major goal for the European Multiple Sclerosis Platform (EMSP). In essence it consists of priorities:

1. The development and piloting of a Register on MS. This register will gather data on people with MS from organisations participating in the project. The advantage of developing this tool on a European level means that the information is known to be comparative across borders. For example, one can assert that a treatment being accessed by 40% of the population of people with MS in one country, may only be accessed by 5% in another country. Without information no light can be shed on the situation of people with MS in Europe.

2. Activation of the Code of

Good Practice MS across the participating organisations with the eventual roll-out to all EMSP members.

Foreseen countries for the pilot study are Germany, Iceland, Poland, Romania, Spain and the UK. These geographically, economically and culturally diverse countries were chosen based on strong discrepancies regarding key areas that are critical for persons with MS, their families and carers, such as:

- (1) disease-modifying therapies
- (2) symptomatic treatments,
- (3) rehabilitation, and
- (4) principles of quality of life.

The establishment of a trans-national data collection system in countries with extremely different conditions will do both, setting a good example for the feasibility of such a project and contributing to the identification of major inequalities between EU countries.

The latest EMSP Council Meeting held on 15 May 2009 has approved the entry of Bulgaria as associate member in the organisation.

**HINTS AND TIPS FOR AIR TRAVEL BY PWMS**

The new EU Regulation is now covering the mobility issue and is the first disability specific legislation. It was adopted in July 2006 and will apply with effect from 26 July 2008 (except some articles regarding denied boarding which are applicable since

*The Society is working hard to acquire accessible premises but our funds are very limited.*

*We therefore would like to reach out to our readers who could help us in raising funds.*

*If you have any suggestions, kindly write us an email on [maltams@gmail.com](mailto:maltams@gmail.com).*

*All donations received are acknowledged.*

*Kindly forward donations to MS Society of Malta, PO Box 63, B'Kara BKR 1000*

## *My Experience with MS - Paul Milano*

I contracted MS at the age of 26 and in the intervening 30 years, I have experienced many forms of the condition from relapsing and remitting to progressive. All these forms have their own characteristics some good and some not so good just like any normal person. In fact one of the ways I cope with this condition is through denial as I have found for many years that denial is the best form of defense. Finding something that interests you is a simple way of conditioning your brain into accepting that you are a normal person and having MS doesn't mean MS has got you! It has taken me a very long time to get to this state. When I was at work in England I suffered a relapse every time I moved sections within the company; the loss of my familiar surroundings was too stressful regardless of how enthusiastic I was about the move. In fact

sometimes being enthusiastic acts as a driver that causes you to overlook the situation, for example buying a new house or new car used to give me terrific excitement but always resulted in a relapse of sorts brought on by stress due to the financial outlay or the effort of accepting change would upset my stability of life.

This all sounds a little technical but it is an accumulation of things I have been told by some very experienced neurologists both here and in England. The truth of the matter is "when you are up then you are up" and able to cope with rigors of the condition and this again is part of the secret. Remember I said I have MS and that is it for me. It could be much worse but for the fact that I can overcome the down spells and enjoy the upside of the condition!

I am determined to write a

book expanding all of my experiences and that is my driving force at the moment. Everyone needs a driving force, whether you have MS or not and that is a goal to aim for. The trick is to make sure that your goals are attainable to offset the pain or mental torment and give satisfaction of achieving things in small doses.

What I am doing now is conditioning my brain to accept smaller chunks of information and be satisfied this way. The brain can rest easily or turn off in sleep which again is something that we need - 'peace of mind'

I used to be a very over excited person so achieving this state has been quite difficult but I know if I can do it so can you!

**Note from Ms Louise Gusman, the President:**

**The MS Society offers subsidized services to members with multiple sclerosis.  
The services include physiotherapy, occupational therapy, speech therapy and psychotherapy.  
For more information kindly contact the Secretary, Mrs Rose Grech on 21496352**

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