

MS Bulletin



HARGA 30 LULJU 2016

Committee members of the MS Society of Malta 2015/2016

Carmen Muscat - President

Alastair Farrugia - Secretary

Christopher Grech - Membru

Mary Buhagiar - Membru

Carmen Muscat - President

Christine Montague - Secretary

**Alastair Farrugia - Assistant
Secretary**

Mary Buhagiar - Membru

Christopher Grech - Membru

Kenneth Muscat - Vice-President

Audrey Micallef - Treasurer

Alexander Degabriele - Photographer

Emmanuel Buhagiar - Membru

Kenneth Muscat - Vice-President

Audrey Micallef - Treasurer

**Alexander Degabriele -
Photographer**

Emmanuel Buhagiar - Membru

IN THIS ISSUE:

◆ EMSP 2015

◆ Assistive Technology

◆ Ten Ways for a happy
life

◆ Mental Health

◆ EMSP 2016

◆ MS Nurse

◆ Photos

A word from the Editor

Welcome all to this year's bulletin. Hope you all enjoy the summer, but make sure to be careful.

Hope to see a lot of new people coming to the Society's meetings and activities to help increase awareness on the condition.

The circumstances and the environment influence our lives but we are the ones who are responsible for ourselves.

A word from the committee members

Dear members I would like to take this opportunity to introduce myself as the new secretary of the society. For those of you who do not know me, I am 53 years old and have been diagnosed for around 6 years, but who's counting. It took me a while to accept MS but now I have embraced it and have decided to make it work for me. I am grateful to the society for giving me the opportunity of attending the EMSP conference as I have returned with very positive ideas that I will share with you as soon as possible. Meanwhile I would like to thank all who have wished me well in this new capacity and hope I will be able to do a good job as Alastair. - Christine Montague

Ever interested in the truth of all things. This is why I love research and ended up working for the NSO (National Statistics Office). Graduate in economics and masters in MBA in strategic management. I try to get to the bottom of many topics, such as health and history and then to share this with people. - Christopher Grech

In the past year, I was the Secretary and now I am the Assistant Secretary. Apart from regular work of the committee (meetings, rapports, emails), I was involved in Olga Bobrovnikova's concert which took place in November, for which unfortunately only 20 persons attended and for a concert which will take place next year. We appreciate the help from musicians and sponsors and the institutions that rent us the hall. Concerts and other activities are nice but the foremost aim is to increase the awareness about MS and the society so that we have funds for the therapies. At the same time we hope that with scientific research there will be better treatments for MS. - Alastair Farrugia

Spring EMSP Conference, Warsaw May 2015

The Spring EMSP Conference in Warsaw was laden with several topics and aspects of MS life. The conference was opened by Anne Winslow, EMSP President and followed by the Polish MS Society. A few videos were presented showing people with MS that still were able to achieve their targets or goals.

There were several presentations regarding the legal aspects of safeguarding MS patients and the proposal of some MS medical therapies from various researchers.

There were also parallel sessions after the coffee break, of which participants choose one option per session. Dee O'Sullivan showed the marvels of mobile applications and tools to cope with MS. I had the opportunity to take part in Whiteman's (cooking for MS) and Sheperdson's (MS & rehabilitation) sessions.

Caroline Whiteman presented an interactive cooking demonstration with various dishes that could be done in a few minutes. Some recipes of hers are scanned and sent to MS members via the MS google group. When I spoke to her about the wheat content, which is not so good for MS, she did acknowledge this fact and she said to change the recipe from wheat to spelt flour instead

and rye is too hard as a substitute.

Lynne Sheperdson gave a lively session with music and exercises for the rehabilitation of MS. We started first on chairs, which would be ideal for wheel bound patients and then work up to standing exercises. While sitting, punching movements were done, first in front of the body, then high up in the air, then to the side. After that, arms swung in a circular motion, left and right arms. Being paired, still in chairs we were given a ball to throw at each other in increasing greater speeds, either a medicine ball or various ball sizes. The idea is to work the mind and nerve connections. It is quite a good workout if you really have a fast partner to catch the ball with. The ball can be thrown in a circular motion, using the left hand and then the right in catching or retrieving it. Good to change direction as well. If the ball falls then one stretches the body with the hand to the ground a few times.

Mikkel Anthonisen, showed us a wonderful video "Sailing Sclerosis: Oceans of Hope" of sailors having MS that together sailed great voyages together unaided. This event provides great encouragement and enthusiasm for life knowing that

even though with MS, we can still do great things, if we want to. They literally sailed around the world. <https://www.youtube.com/watch?v=XLRI14kzyU> is the video of these volunteers.

Trishna Bharadia is a determined British girl who was chosen to participate in a TV programme and to show that persons with a disability can still be seen to be marvelous in their skills. The MS should not impair anyone from being who you want to be. A film "Welcome back - Dancing for MS", of her dancing was shown to all present at the conference, and she gave her personal story on how she was chosen out of all contestants to be on this show and on her viewpoint about her MS condition.

The last video shown, "Estonian Under Pressure" by Claudiu Berbece and Katrin Ruutel is a sweet romance of MS persons, whose love-life although 'impaired' shows great love, respect and great humour to cope with this situation.

Tomasz Polec, the representative of the Polish State Fund for Rehabilitation of Disabled People, spoke of the long experience of MS societies in his country. There are many members

who formed regional societies in their country. They are not so supported financially as are in some wealthier EU member states.

Now for some highlights of MS therapeutic improvements for MS patients.

Prof Krzysztof Selmaj was seeking to improve the therapeutic treatments for MS patients and to try to work with government on finding a solution for second line treatments, or follow-ups, to have a more comprehensive care. Christoph Thalheim and Yves Furet, spoke of a German Treating MS online tool that seeks to address details about MS patients and between relevant health departments.

Dee O'Sullivan, Simone Pereira, Mick Foy, showed a UK project to integrate various information regarding patient records into a more integrated system. The issue of confidentiality was discussed and the patient decides on the level of permissions that are accessed by the health authorities. This may provide a tool to find out more about the cause of MS and other issues.

Gabor Petri worked on a UN Convention on the Rights of People with Disabilities. As some member states

Continue ...

may not even abide by their own national laws to help persons with disabilities, or as signatories to UN charters, a new approach is to enforce what most UN member states already signed to help disabled persons, and to implement it in a more concrete way.

As in Malta, some public entities have to engage a percentage of disabled persons in employment, this can be extended also to the private sector. We may have a new UN level of agreement, and Petri would try to force the issue to implement what the member states have already signed, but then to translate this and implement it in the real world.

The "Believe & Achieve" project by the Work Foundation provided temporary employment as interns for people with a disability. Shana Pezaro and Stephan Bevan spoke of their employment internship for a few months to gain working experience. They spoke of the success stories behind it. However when I found out that it was only pharmaceutical companies that were doing so, there was perhaps an ulterior motive behind this plan? The companies' motives may therefore not be completely altruistic. The whole society, including the corporate world, needs to take on more responsibilities to aid people with special needs.

This 'PACT' is a scheme to engage organizations to volunteer and come on board to aid society with obtaining skills from MS patients. Rather than having society putting all the burden to help people with certain disabilities, the business world can also help out. By allowing flexible hours and other things, this should be a win-win situation for all parties concerned. For more information about this PACT, see:- http://www.emsp.org/attachments/article/299/EMSP_PACT.pdf

The next MS general conference, would be held in Oslo, Norway. When meeting informally with Anne Winslow, I remarked on the bias of the traditional doctor and Western medicine approach. There were no alternative health treatments at this Spring Conference. She agreed on principle to next time have a more balanced approach. I promised her support, should I know of alternative treatments. Yves an official of the EMSP staff has totally agreed with me on bringing on board other health practitioners and ideas to help overcome MS.

Christopher Grech



Assistive Technology and Persons with Disability

Persons with disabilities now live longer, therefore we have to provide services that increase their quality of life.

Assistive Technology (AT) is one of the answers. It has REDEFINED what it is to have a disability: from the MEDICAL MODEL to the SOCIAL MODEL.

Philosophy behind AT Service delivery:

The **consumer** is the primary member of the interdisciplinary team and must be considered an expert and thus the **consumer** is at the center. Family, carers and professionals are facilitators and supporters. AT services are primarily delivered in non-traditional medical models, therefore **consumer or user, not patient.**

An individual's support system consists of:

- ◆ Assistive Technology - Tools
- ◆ Personal Assistance Services – Cooperation
- ◆ Adaptive or Compensatory Strategies – Techniques

AT is being increasingly integrated into rehabilitation services

Professionals have to know what is available with regards to: AT Types, AT Applications, AT Services, AT Resources

AT Service Providers work in a variety of settings:

- ◆ Hospitals
- ◆ Rehabilitation centers
- ◆ Schools
- ◆ Workplaces
- ◆ Independent living centers



Four elements need to be considered in any AT service:

- ◆ the CONSUMER
- ◆ the TASK to be performed
- ◆ the ENVIRONMENT where the task is to be accomplished
- ◆ the ASSISTIVE DEVICES that can facilitate this activity

The Dilemma:

For many persons with disabilities, their families and the professionals who work with them, the world of technology is complex, mistrusted, expensive, inaccessible, unavailable and constantly changing.

Problem solving approach:

AT application is complicated: each individual has individual needs; environments where devices are used vary. Since there are so many variables, there is not one solution to any one problem - a problem solving approach has to be used.

Interdisciplinary Approach:

The collaboration, communication, and coordination of effort by the rehabilitation team working with a person with a disability is essential for effective AT service delivery.

It is impossible for all professionals to keep abreast with ALL areas in AT, so it is important to work together and share knowledge and experience.

Ms. Vickie Gauci

Ten Ways for a Happy Life

Be Humble

- * **Accept** your limitations
- * **Care** more about what is true than who is right
- * Be **open** to criticism and corrections
- * Humility requires emotional strength, confidence, inner maturity and emotional independence from others' opinions. It opens opportunity to learn & grow.



Personal growth **LEADS TO MORE JOY IN YOUR LIFE**

Be Courageous

- * Loving the loveable is easy but loving the unlovable takes courage
- * **Honesty** when telling the truth requires courage
- * **Confront** weakness
- * **Try** something you have never done before
- * **Grab** hold of life changing opportunities
- * **Open** your heart again after it has been broken



Be Grateful

- * **Notice** the light in the dark

Be Tolerant

- * **Tolerate** others mistakes.
- * **Tolerate** the uncertainties of life.
- * Live comfortably with change, disruption, opposing ideas etc.

Be Loving

- * Love is the great neutralizer of negativity
- * See pain behind anger
- * Reach out with kindness and compassion for those who strike out in fear and blame

Love truly does conquer all

Be Forgiving

Weight of grudges disfigure us with hate and resentment. By forgiving others and ourselves, we become free of these negative feelings.

Forgiveness – helps us to be happy

Be Honest

- * Be true to others
- * Be true to your self



Be Persistent

* Life is full of obstacles, of difficulties and challenges, sorrow, pain and trials.

Do not give up -- Hope is a virtue

Be Patient

- * Allow room to learn, to fall and trip.
- * Be patient with others
- * Be patient by accepting the common lot of imperfect humanity and recognizing the potential in each one of us.

Connie Magro (psychiatric nurse)



Leading a Meaningful Life helps your Mental Health

Signs of good Mental Health

- Ability to form relationships, care for others and love them
 - The ability to engage and desire to indulge in interaction and the expression of emotions.
 - The ability to engage in work to overcome problems, control anxiety, bear loss and be able to cope with changes in life
 - A sense of reality in such a way that there is a clear separation, from the internal fantasy world and external reality, also in difficult and stressful situations.
 - Being socially independent, having a well-developed identity and individual creativity

Areas of influence— Mental health promotion



To be mentally healthy you need

- Flexibility
 - Innovativeness
 - Creativity
 - Connectivity
 - Social skills
 - Ability to cope with change

Threats to your mental health

- Exclusion
 - Poverty
 - Illness
 - Loneliness
 - Noise
 - Alcohol & Drug abuse



Look after your mental health

- Talk about your feelings
 - Keep active
 - Eat well
 - Drink sensibly
 - Keep in touch
 - Take a break
 - Care for others
 - Do something you are good at
 - Accept who you are
 - Ask for help



The only constant is change

The only constant is change
Everything changes but not on its own. You change everything but not alone.

Connie Magro (psychiatric nurse)

PHOTOS TAKEN THROUGHOUT THE YEAR



Meeting with Ms.
Vickie Gauci

Meeting with
Ms. Connie
Magro



Piano concert by
Mandy Francalanza

Celebrating
World MS Day
with Mr. Oliver
Scicluna



Spring EMSP Conference, Oslo May 2016

This was a first for me and to be honest I didn't know what to expect. Getting to Oslo was quite a long affair as I was travelling for 10 hours to a country I hadn't seen in 18 years.

When I sat down to the AGM on Monday afternoon everyone seemed to know each other and I soon entered into the spirit of things. The reading of the minutes and financial report was straightforward enough, as was the voting for various motions. The MS Society of Malta had been given the minutes of the previous year and the financial report by email, any differences were pointed out and explained. For example, rise in salaries was due to the beginning of a pension fund for employees of EMSP.

The final vote was taken for a young person's representative for EMSP. Jana Hlavacova was elected. Some might remember her as taking part in the online conference we had attended at The Palace in Sliema. Somehow this gave me a sense of knowing someone there.

Tuesday was very intense. We had an early start and spent the morning celebrating the Norwegian National Holiday watching the Parade to the Palace. Definitely exhausting but different!

After a quick lunch we were inundated with presentations of different research programs. Amazingly the greatest difficulty presented for persons with MS was chronic fatigue, and this when quantified was on average between 67% and 70%. It was recognised as being the greatest difficulty faced and affected the wellbeing, career, social and family commitments of the patient.

The message that came through following all the presentations was we had to feel empowered with all this data and demand that our requirements are considered at national level. To quote the president Anne Winslow 'we need to make our voices heard.'

We attended a lovely Gala dinner and by this time I had gotten to meet and recognise a number of people. Especially funny when sitting at table, one of the other members, Costas of Greece said, "Let me introduce this side of the table. I am Costas and here we have Maia of Latvia."

She was one of the people I was supposed to meet up with and had been looking for her all day.

Obviously in true Christine fashion I answered as loud as Costas, "Maia of Latvia I have been looking for you all day!"

This broke the ice and I am proud to say we were the loudest table there and had a fantastic time.

I suffered for all the Tuesday activities as I woke up Wednesday to a very early start and was again bombarded with further details regarding new developments. This time it was directed to what we as patients should be doing, again supported by studies.

Continued...

So, what should we be doing? In a nut shell:-

We have to demand recognition of our needs.

We should demand respect from our neurologists and MS nurses.

A neurologist should begin with asking how we are feeling, if we are having difficulties at work, in relationships.

If the medication does not agree with us it must be changed.

Diagnoses should be made with first symptoms and not wait for a second relapse.

Medication should be prescribed immediately.

MRIs should be interpreted in greater detail and not just look at the number of plaques but look for brain atrophy.

MRIs should be explained in detail to the patient.

An MS nurse is an important point of contact and coordinates between the patient and the neurologist.

An MS clinic brings all professionals under one roof so when the patient has an appointment he/she can be supported all round.

Progress needs to be recorded.

There is going to be an European Registry, data will be given at national level.

There must be a National Registry and data needs to be supplied by the patient.

EMSP is being consulted at various levels.

There is to be European funding for research independent of the pharm industry.

Do you feel like I did at the time? I felt like OMG where do we begin in Malta?

So I came back feeling very empowered, confident that we have the backing of EMSP. We should participate in all their data collection projects like 'Barometer'.

All voices together will be heard and respected at European level. Participating with EMSP will give us in Malta identity!

I could not believe how these 3 'packed solid' days flew past and was disappointed to leave but came back to Malta full of ideas to discuss and implement.

Christine Montague



Photos taken throughout the year



Celebrating World MS Day with Hon. Parliamentary Secretary Dr. Justyne Caruana

Meeting with Ms. Anabel Mifsud



AGM

Buffet
BBQ



MS Nurse

I wonder how many MS patients in Malta know what an MS Nurse is and does. I certainly did not until I looked into it and realised how having the services of an MS nurse and the set up of a multidisciplinary team is helpful to us all. So I looked into the possibilities.

It would be interesting to know some background history. The European Multiple Sclerosis Platform (EMSP) launched the MS Nurse Pro programme here in Malta. This is an e-learning curriculum in 5 modules that any nurse especially ones who are interested in Neurological diseases/disorders can specialise in. There are 3000 registered MS nurses all over Europe and the programme has generated interest as far as South Africa and Mexico.

The MS nurse gets to understand the disease, its presentations, diagnosis and assessments, the patients' cares and needs. The nurse does not do the job of a neurologist but supports both neurologist and patient. He/she is the go between, at times just a phone call away when the patient or their carers have a difficulty. The nurse can be present on the ward and at the MS clinic and attend an appointment with the neurologist when the patient requests his/her support. Having an MS nurse available in Malta would mean more appointments and contact with support from hospital. More updates on availability of medicines, therapies and alternative treatments. It would also help the neurologist to have a more holistic view of the patient, their background and their needs. The nurse can evaluate the patient's individual needs and help build a treatment programme and monitor the progress of the disease.

It is a shame that something as worthwhile as this programme, whilst having been initiated in Malta, has lost the interest of the medical community. Carmen Muscat, as President of the MS Society in Malta and the committee feel the importance of having the MS Nurse Pro programme reinstated in Malta, that we will be working towards this aim with the support of EMSP.

*Hope is when against all odds
a tiny flame keeps burning
for the possibility. - Tilicia
Haridat*

*When the door of happiness closes,
another opens but often we look so
long at the closed one we don't see
what was open for us.*

BENEFACtors' LIST 2015/2016

Malta Community Chest Fund	Support to Voluntary Organisations	Lombard Bank Sliema	Polymer Pharmacy Zabbar
Felice Pharmacy Zabbar	Consolidated Biscuits	Trading Post Sliema	Jan Sammut / HSBC
B4 Textiles Fgura	A.P.E Zabbar	Crosswinds Charity	Abercorn Lodge
Palmyra	Lions Club Mdina	Actavis Bulebel	Matthew Ellul
Voices	Olga Bobrovnikova	Beauty Parlour	Jester Pub
Two Cherries	Eurosport B'Kara	Mr & Mrs Izzo	Mandy Francalanza
Sanofi	Novartis	Ms. Mary Cassar	Nick Bonnici
Marks & Spencer	BHS	St. Anne's Clinic	Foster Clarks
D&M Styling Zabbar	Ta' Karla Cash and Carry Rabat	St Catherine Pharmacy Attard	Paloma Ironmongery
BOV B'Bugia	Goodies B'Kara	Ernst & Young	Clayton Caruana
Smart Offices Supplies LTD	Red Lion Bar Qawra	Maltco Lottery Branch Lija	CSH Class 1980
Tony Cassar Xemxija	Nestor Jacono / Agapi Trust	Stella Maris Pharmacy Sliema	Ganado Trustees & Funds
Expressions	Ms Attard	Mr Bonello	Mr & Mrs Alden
Claire & Keith	Family Delia	Family Buttigieg	Family Radoligo
Mr & Mrs J Felice Pace	Dar tal-Providenza	Ms Pace & Ms Ton- na	Mr T Sammut Alessi
Ms Salvina Bondin	Family Zerafa	Mr Vassallo Grant	Kullegg San Nikola Mtarfa

Editur: Tatiana Muscat

Typesetting u dizinn: Tatiana Muscat

Mitbugħ: Mr Jesmond Arpa, Five Star Printing Ltd.

Multiple Sclerosis Society of Malta, Address: PO Box 63, B'Kara BKR1000

Tel: (+356) 27 806 127

E-mail: info@msmalta.org.mt

Website: www.msmalta.org.mt

SMS: 5061 8941 For € 6.99 donation

Bank Account: Swift Code (HSBC Bank Malta P.L.C.) : MMEBMTMT

IBAN: MT97MMEB44163000000016196495050

www.facebook.com/MultipleSclerosisSocietyOfMalta

