



# MS Bulletin

Harga nru. 17 - Jannar 2005

## Messaġġ mill-President...

Ftit tal-jiem ilu sellimna lis-sena 2004 u tajna merhba lis-sena l-gdida. Ghaddiet sena ohra minn fuqna, sena li fiha qsamna flimkien hafna attivitajiet li, b'xi mod jew iehor, ghenu biex itaffu l-piz li ggib maghha l-multiple sclerosis.

Il-messaġġ tieghi ta' llum hu li ma noqoghdus inharsu lura jekk mhux biex nitghallmu mill-izbalji jew nuqqasijiet tal-imghoddi u biex nizguraw li ma nirrepetux l-istess zbalji. Minflok, irridu nharsu 'il quddiem u nsaqsu lilna nfusna "X'se naghmlu matul is-sena l-gdida?" Hemm bzonn li jkollna ghanijiet li rridu nilhqu u proġetti li rridu nirrealizzaw.

(Ikompili fl-ahhar pagna)

## ...mis-Segretarja

Dear members

I would like to thank you for the support you have given the Committee members throughout this year. I sincerely wish that next year we will manage to start the psychotherapy sessions in smaller groups if funds permit. I would like to encourage any new members who would like to come forward and give some of their time to the Society, be it fund raising, administrative support or any other commitment they would like to give to the Society. I wish you all seasonal greetings.

Louise-Anne Gusman - Secretary

## ...mill-Vici-president

Meta ahna naghtu, ahna naqilghu. Hekk jghid il-Vangelu. Hu facli hafna li ddahhal idejk fil-but u taghti xi haga tal-flus biex traqqad il-kuxjenza. Izda kemm hu ta' sodisfazzjon meta naghtu ffit tal-hin minn taghna biex nghinu lil haddiehor, l-aktar meta nkunu nistghu naghmlu dan. Is-Socjeta taghna hija ghal dawk kollha li jbatu b'din il-kundizzjoni. Izda ghaliex dejjem l-istess nies jattendu ghal-laqghat taghna? Ghaliex dejjem l-istess nies li joffru l-hin tagghom? Li tbatu minn din il-kundizzjoni mhix xi haga li wiehed ghandu joqghod idoqq it-trombi dwarha, izda lanqas ma hi xi haga ta' misthija. Hadd ma gabha b'idejh.

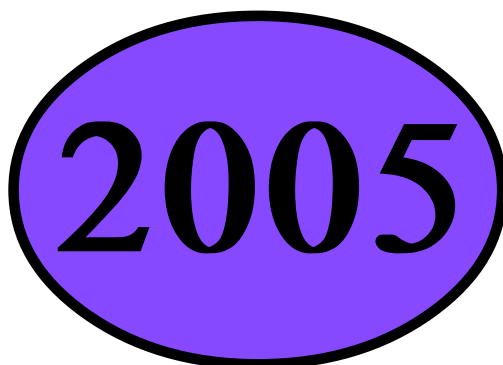
(Ikompili fl-ahhar pagna)

## ...mit-Tezorer

Dear members

I am writing this message in English to reach out also to the English speaking persons with MS who need to come forward to receive and to give the support for a condition which has no gender and no language. We have gone through the season of Advent in which we all waited for the coming of HIM who brought HIS Light into the world of darkness, that we may all find in HIM the strength and the hope that only HE may give us: "come to me you who are burthened, and I will give you rest". May the Light that Christ brought into the world brighten the lamp of your hearts that you may bring His Light into your lives and the lives of all those who find Him in the centre of your sufferings.

Godfrey Leone Ganado - Treasurer



# Attivitajiet

» F'Ottubru li għadda l-kelliem mistieden kien Dr Norbert Vella, consultant neurologist u l-konsulent mediku tas-Socjetà tagħna. Fit-taħdita mill-aktar interresanti li tana, huwa tkellem dwar l-ahhar żviluppi fil-qasam tal-MS. Kif kien mistenni, il-membri prezenti apprezzaw hafna din it-taħdita.



» Fl-okkazjoni tas-seba' sena mit-twaqqif tas-Socjetà tagħna, fit-30 t'Ottubru kellna mistednin lil Joe id-Dulli u lil Veronica Farrugia li ferrhu lill-membri tagħna biċ-ċajt u l-kant tagħhom. Barra minn hekk, il-membri setghu ibillu grizmejhom u jieklu xi haga hafifa li żgur li nizlet għasel f'dan l-ambjent ferrieħi u familjari.

» F'Novembru reġa' kellna taħdita mill-psikoterapista Ms Caroline Mallia. Il-membri ma naqsux milli jieħdu sehem attiv hafna fid-diskussjoni. Hafna membri qed isibu dawn id-diskussjonijiet ta' fejda kbira għaliex matulhom qed ikollhom l-opportunità li "jizvugaw" xi ftit u jaqsmu hsibijiethom ma' haddiehor.



» F'Dicembru, il-membri ltaqgħu flimkien f'restaurant ta' lukanda ewlenija għall-ikla tal-Milied. L-attendenza kienet tajba hafna, u l-ikla kienet abbondanti u ta' livell għoli. Matulha ttellgħu bix-xorti għadd ta' rigali sbieħ. Dawn ir-rigali ngħataw bil-generozità tas-Sur Simon Soler, benefattur tas-Socjetà.



# Editorjal

## Tama fil-Gejjieni

Il-hajja stess ta' kuljum turina li ahna dejjem qegħdin nistennew li l-aħjar għad irid jasal u għad irid jintlahaq. Huwa proprju dan it-twemmin li jwassal lix-xjentisti, lill-inventuri u lir-riċerkaturi ma jieqfu qatt minn xogħolhom, fit-tiftix kontinwu għal dak li huwa aħjar.

L-aħjar kura għad trid tinstab.

L-aħjar mediċini għad iridu jiġu żviluppatti.

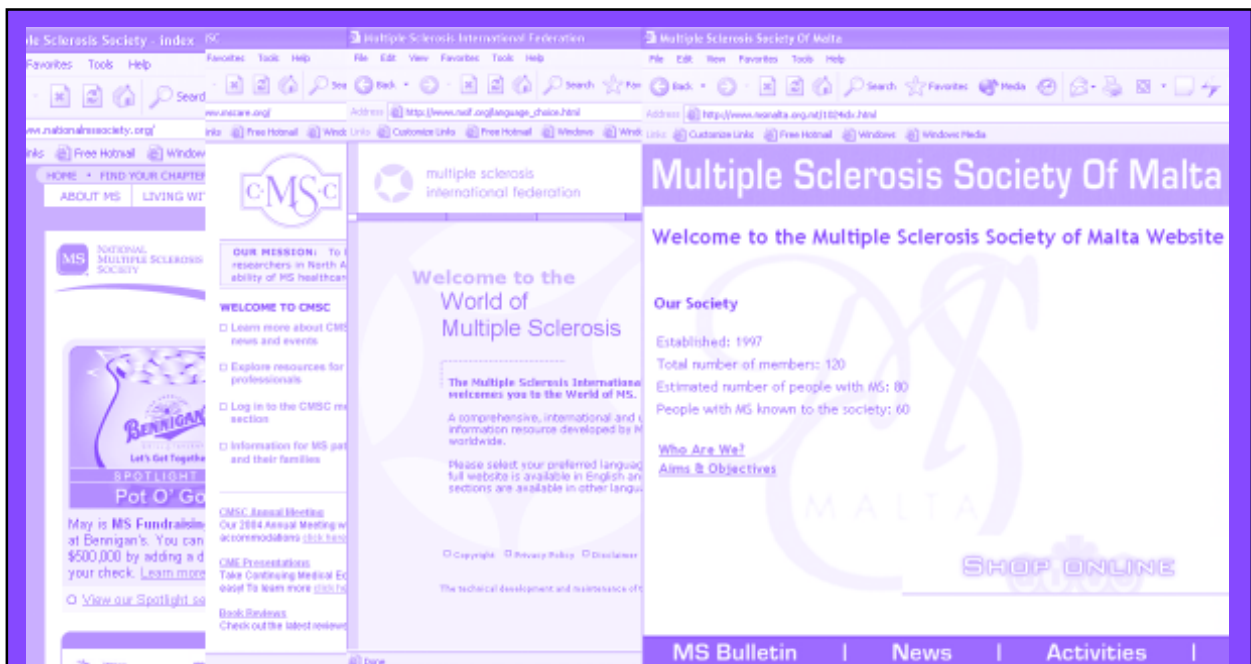
L-aħjar sptar għad irid jinbena.

L-aħjar tobba għad iridu jiġgradwaw.

L-aħjar soċjeta' għad trid tiżviluppa.

L-aħjar ... għadu ġej! Hija stqarrija li taghti t-tama ... li l-hajja għad trid taghti aktar opportunitajiet, u aħjar minn dawk li kellna s'issa. Ix-xewqa għal ġejjieni aħjar iġġib magħha l-ottimizmu. Meta, imbagħad, dan l-ottimizmu inlaqqghuh ma' ippjanar bil-għaqal u hidma serja, ir-rizultati miksuba jkunu mill-aqwa. Ikun tajjeb li l-fjamma tat-tama fl-aħjar li għad irid jasal inzommuha dejjem tixghel f'hajjitna. Is-sena t-tajba lil kulhadd.

Dr Martin R. Zammit



## Websites Importanti

[www.msif.org](http://www.msif.org)

[www.msmalta.org.mt](http://www.msmalta.org.mt) (il-website tas-Soċjeta' tagħna)

[www.nationalmssociety.org](http://www.nationalmssociety.org)

[www.mssociety.org.uk](http://www.mssociety.org.uk)

[www.ms-gateway.de](http://www.ms-gateway.de)

[www.ms-care.com](http://www.ms-care.com)

# Rapporti

## EMSP/EVS Cyber café Project: Final Evaluation Seminar

Birmingham 7th – 9th July 2004

The Final Evaluation Seminar of the EMSP/EVS Cyber Café Project was held on 7th July 2004. I was asked to attend this final seminar as a supervisor together with our EVS volunteer Daria Urbanczyk who had spent a whole year here in Malta.

During the seminar the supervisors together with the volunteers had to prepare visual or printed material about their respective Cyber Café project. An exhibition of posters, photos, booklets, leaflets was set up where the volunteers related their experiences. Some had very good experiences in an already set up facility, others did not get on very well with their supervisor. Our volunteer Daria, had a hard time at the beginning to try to set up the facility because when she arrived in Malta the computer laboratory at the Marsascala Friendship Park had not been set up yet and internet access was not available. In the meantime Daria, with the help of Multiple Sclerosis Society of Malta Committee members, was helped to integrate in the Maltese community. Daria enrolled on a course to learn the Maltese language. Contacts were made for her to enrol in a female volleyball team. Her host family was tremendously helpful and gave her a very warm welcome and stay. In fact, it was taken into account that, for future projects, host families would be ideal to help the volunteers integrate well in a foreign country and not left alone in a flat or hostel.

Daria organised a weekly session of computer lessons for our MS members. After a few months she added another session so that our members could have more time to practice computing.

I would like to thank Mr Andy Bevan who was very organized and tremendously helpful to all the participants. Mr Bevan encouraged us to try to continue the project as an "independent" EVS project. I would also like to thank Mr Christoph Thalheim who could not be with us during the Final Evaluation due to other EMSP commitments. My final greetings go to the staff of Harbourne Hall who worked non stop and also organised various activities each day to help the tutors, students, supervisors, trainers, disabled personnel and volunteers feel at home.

Louise Gusman - Secretary



## CAPTION

### *MS in Focus*

*Titlifix l-opportunità li żżomm ruhek infurmat dwar il-Multiple Sclerosis billi tikseb b'xejn kopja tal-MS in Focus mahrug mill-Federazzjoni Internazzjonali tal-Multiple Sclerosis. Dan il-perjodiku johrog darbtejn f'sena, sew f'ghamla stampata kif ukoll fil-forma ta' fajl PDF li jinqara permezz tal-Internet. Fil-ħarġa ta' Jannar taqraw dwar kif tistghu tghixu b'saħhitkom. Biex tabbonaw idhlu fis-sit: [http://www.msif.org/en/publications/ms\\_in\\_focus/index.html#free](http://www.msif.org/en/publications/ms_in_focus/index.html#free)*

*Have you subscribed to MS in Focus? Sign up for it now - the next issue, 'Healthy Living' will be published in January 2005. MS in Focus is produced twice a year by MSIF in both paper and PDF versions. MS in Focus is available to all those affected by MS worldwide, produced by an international cross-cultural board, easily accessible language and free subscription. To subscribe, log on to: [http://www.msif.org/en/publications/ms\\_in\\_focus/index.html#free](http://www.msif.org/en/publications/ms_in_focus/index.html#free)*

# Rapporti

## Excerpts from the report on the seminar: “From Compliance to Adherence in longterm MS Therapies” – Brussels, 19 – 20 Oct 2004.

**Ms Connie Carabott, Ms Daniela Abela and Ms Margaret Abela**

**The meeting was also attended by MEP Joseph Muscat, an activist in the field of disability**

Lately our Society has been invited to send delegates, free of charge, to attend seminars abroad. These regular invitations are among the advantages of our Society's membership in European and international societies.

**Hans Peter Hartung (Germany):** Patients with MS must seek to improve themselves through the use of currently available pharmaceuticals. He reiterated that patients not making use of prescribed pharmaceuticals are seriously denying themselves of the benefits linked with these drugs. It is estimated that 50% of persons suffering from chronic MS do not habitually and consistently adhere to what has been prescribed to them. Persuading patients requires the collective efforts of multi-disciplinary teams.

Dr Hartung stressed that the treatment slows the disability, reduces the relapse rate, reduces inflammation, reduces progression of brain atrophy, slows the progression and improves the quality of life. Studies show that 70% failed interferon treatment and 20% discontinued within the first 6 months of therapy. He stressed that those who discontinue the treatment after 6 months, will not benefit. People tend to give up because of side effects, but it is important that one should take the Beta Interferon.

Dr Hartung spoke about the importance of a multi disciplinary team consisting of the neurologist, the family doctor, the nurse (whose role is to help and provide education, counseling, support and advocacy), the expert person who gives information about coping with the disease and improving the communication with health care providers and friends, and finally support programmes. He concluded that patients need also to be supported by MS societies.

**Fiona Stevenson (UK)** delivered a brief outline of the report: “Adherence to long term therapies and findings of the W.H.O.” She looked into the problems encountered, definitions, key messages, key challenges, concordance and conclusions. She stressed that if the country can afford the drugs, the people can make use of them for their own benefit. She ended her speech by stressing that professionals need to be trained in adherence.

**Ralf Gold (Germany):** Adherence in MS (a neurologist’s view)

Dr Gold stated that we need to make good use of the available pharmaceuticals, namely Avonex, Beta Interferon, and Rebif. He stressed that it is very important to treat the patient as early as possible. He also stated that the MRI gives quick and definite diagnostic results.

**Vicky Gutteridge (UK):** Treatment persistence in MS patient support techniques.

Ms Gutteridge made reference to: greater active participation, psycho-educational model, careful assessment of expectations, understanding and constraints, judicious use of product information, group support, networks, and finally websites and IT (UK). A good website is [www.msdecisions.org.uk](http://www.msdecisions.org.uk).

She spoke about the various phases of treatment. She stated that treatment should fit in well with life commitments. She also spoke about the side-effects related to treatment, such as skin reactions, flu-like symptoms, increased spasms and stiffness, chest tightness, breathlessness, headaches, mood changes. It is therefore important that there should be lifestyle guidance, symptom management, continued monitoring expectations, specific support services, help lines, product magazines, websites and important contacts.

Finally Ms Gutteridge insisted on the need to persist with the treatment. She concluded her speech by saying “But Remember The Unpredictable”.



**Robert Shlathau (Austria):** From compliance to adherence in Multiple Sclerosis long term therapy (a patients' view)

Mr Shlathau spoke about the physical conditions of MS, the psychological aspects, the side effects of drugs and allergic reactions and the lack of communication. As there are different medications for different persons with MS, he stated that he wants to see a multidisciplinary team like family, friends, neurologists, doctors, nurses, and physiotherapists, within a framework of nursing and social services. Mr Shlathau concluded by saying that "TOGETHER WE CAN MANAGE THE PROBLEM".

At the end of the conference an MS information hour was held at the European Parliament.

## Il-messaġġ tal-President

Nofs hajjitna hija magħmula mill-holm - holm li hafna drabi ma jsehħx. Imma l-holm jagħtina dik l-ispinta biex nippruvaw naghmlu xi haġa. Ma jimpurtax jekk noholmu mitt haġa imma fl-aħħar nkunu għamilna biss għaxra minnhom. L-importanti li dejjem ikollna holma jew tnejn quddiem għajnejna li jzommuna okkupati, għaliex wahda mill-agħar sitwazzjonijiet li nistgħu nidhlu fihom hi li ma nidhlu għall-ebda attivita' għax naqtgħu qalbna.

Il-hajja hi ferm isbah meta nistgħu nieħdu soddisfazzjon b'dak li nkunu qed naghmlu, sew jekk ikun ghalina, iżjed u iżjed jekk ikun għal haddiehor. Għalhekk, eja naghmlu kuragg u nibdew billi noholmu ffit x'nixtiequ li nwettqu f'dawn it-tnax-il xahar li ġejjin u, wara li nkunu hlomna, nibdew nahdmu biex inwettquhom. L-importanti hu li ma nhallu lil hadd u lil xejn jaqtagħlna qalbna. Iżjed ma neghelbu diffikultajiet, ikbar ikun is-soddisfazzjon.

Is-sena t-tajba lil kulhadd

Leslie Agius

## Il-messaġġ tal-Viċi President

Għandna nkunu ffit generuzi, umli biżżejjed biex niltaqgħu ma' min, bħalna, ibati bl-istess kundizzjoni. Il-prezenza tiegħek tagħmel differenza, u hi biżżejjed biex tagħmel kuragg u tagħti support li min jehtieg. Is-Socjetà tagħna torganizza laqgħat ta' kull xahar għall-ġid tagħna stess, u minnhom jibbenifika kulmin jattendi. Nixtiqilkom sahha, hena u l-festi it-tajba.

Ms Rose Grech