

## Il-Laqgħa Ġenerali Annwali tas-Socjetà Rapport ta' Hidma

**1. Il-Kumitat:** Il-Kumitat inhatar waqt il-Laqgħa Ġenerali tas-6 ta' Marzu



2004 u huwa fformat minn dawn il-membri: Mr Leslie Agius, President; Ms Rose Grech, Viċi President; Mr Godfrey Leone Ganado, Tezozier; Ms Louise Anne Gusman, Segretarja; Dr Martin Zammit, membru u l-Editur tal-Bulletin; u Dr Norbert Vella, Chairperson tal-Bord Mediku.

Il-Kumitat iltaqa' tmien darbiet matul is-sena 2004 biex ihejji programm ta' attivitajiet u jiddiskuti fuq problemi li jinqalghu matul is-sena. Il-Kumitat jistudja ukoll liema hu l-aħjar pjan sabiex is-servizzi tal-fizjoterapija, tal-psikoterapija, u s-servizz ta' trasport b'xejn għall-membri bl-MS meta jattendu l-laqgħat tagħna jew attivitajiet ta' rikreazzjoni jibqghu għaddejnin regolament. Dawn is-servizzi huma ssussidjati mis-Socjetà stess.

**2. Is-Sotto-Kumitati:** Bl-ghajnuna tas-sotto-kumitati l-ghanijiet tas-Socjetà jintlahqu aħjar. Il-President u s-Segretarja ex-ufficio jattendu għall-laqgħat ta' kull sotto-kumitat.

**Is-Sur Leslie Agius,  
President**

*a. Is-Sotto-Kumitat tal-Ġbir tal-Fondi: Mr L Agius, Ms L Gusman, Mr G Leone Ganado, Ms Elizabeth Agius Fenech, Mr Simon Soler*

Dan il-Kumitat għandu kuntatti ma' entitajiet li jistgħu jghinu lis-Socjeta, u jiehu hsieb it-tqassim u l-ġbir tal-bottijiet. Din is-sena il-Kumitat qabbad lill-membri tas-Socjetà sabiex huma wkoll jghinu fil-ġbir ta' fondi tant mehtieġa għas-servizz tal-fizjoterapija u tal-psikoterapija. Din is-sena konna wahda mis-Socjetajiet li bbenifikaw mill-Maratona tas-Sbuhija u Xagħar li saret bejn il-Hadd 21 u it-Tnejn 22 ta' Marzu fi Studio 7, B'Kara. Nixtiequ niringrazzjaw lil Direttur tal-Istitut tas-Servizzi tal-Komunità,

Ms Dorothy Meli, l-istaff u l-istudenti tagħha, kif ukoll lill-membri tagħna li taw l-għajnuna tagħhom matul il-jumejn tal-Maratona.

Nixtiequ nirringrazzjaw lil Ms Elizabeth Agius ta' l-għajnuna li tat f'dawn l-aħhar snin fit-tqassim u l-gbir tal-bottijiet. Nixtiequ nirringrazzjaw ukoll lil Mr Simon Soler li qed jikkontribwixxi fondi lis-Socjetà fuq bażi regolari.



**Mr Godfrey Leone  
Ganado, Tezozier**

*b. Sotto-Kumitat għall-Edukazzjoni u*

*Informazzjoni: Mr L Agius, Ms L Gusman, Dr Martin Zammit, Mr Noel Gusman*

Il-Bullettin jiġi ppubblikat regolarment tliet darbiet fis-sena. Nirringrazzjaw lil Dr Martin Zammit u ibnu s-sur Stefan Zammit tal-hidma tagħhom fit-thejjja ta' dan il-Bullettin. Nirringrazzjawhom ukoll talli jzommu l-website tas-Socjetà aġġornata.

Dr Zammit, Viċi President tal-Federazzjoni Għall-Organizzazzjonijiet Persuni B'Dizabilità, u Ms Carabott, membru tas-Socjetà, jattendu regolari għall-laqgħat tal-Federazzjoni.



**Is-Sinjura Rose Grech,  
Viċi-President**

*c. Sotto-Kumitat - Attivitajiet oħra –  
Għajnuna lill-membri: Mr L Agius, Ms L  
Gusman, Ms R Grech, Ms C Carabott, Ms  
M Buhagiar, Mr M Buhagiar*

Dan is-sotto-kumitat jgħin sabiex insiru nafu iżjed mill-qrib lill-membri tagħna u nifhmu aktar il-problemi tagħhom sabiex ngħinu lilhom u l-familja tagħhom. Nirringrazzjaw lill-membri ta' dan is-sotto-kumitat għall-bosta żjarat li għamlu f'diversi djar tal-membri.

*d. Sotto-Kumitat Attivitajiet Soċjali: Mr L Agius, Ms L Gusman, Ms P Tabone, Mr J Tabone*

Dan is-sotto-kumitat jieħu ħsieb l-ibbukjar tat-trasport għall-membri tagħna biex jiġu l-laqgħat kif ukoll ifittex postijiet tad-divertiment aċċessibli sabiex l-attivitajiet soċjali jkunu ta' success. Bil-kooperazzjoni tal-membri, l-attivitajiet tagħna jistgħu jizjedu. Fl-okkażjoni tas-seba' sena mit-twaqqif tas-Soċjetà stedinna lil Joe id-Dulli u



**Mr Joe u Phyllis Tabone**

Veronica biex iferrħu lill-membri tagħna. Nirringrazzjaw lil Joe u Phyllis Tabone ta' l-ghajjnuna li jagħtu matul is-sena u lil Rose Grech tal-hidma tagħha li twassal biex kollox imur sew.

*e. Sotto-Kumitat Relazzjonijiet Internazzjonali: Mr L Agius, Ms L Gusman, Dr M Zammit, Mr N Gusman*

Ix-xogħol ta' dan is-Sotto-Kumitat hu li jzomm kuntatt ma' organizzazzjoniet internazzjonali tal-MS biex permezz tagħhom insiru nafu kif pajjizi ohra qegħdin jahdmu fl-interess tal-persuni bl-MS. Rivisti li jaslu minn barra jinflew sewwa u dak li jkun ta' interess għall-membri jiġi ppubblikat fil-Bulletin.

Mr Noel u Ms Louise-Anne Gusman irrappreżentaw lis-Soċjetà waqt l-ahħar Seminar tas-Cyber Café' (Birmingham, Lulju 2004). Rapport dwar dan deher fl-ahħar harga tal-Bulletin.

Ms Connie Carabott u Ms Daniela Abela, akkompanjata mill-mamà tagħha Mrs Abela, irrappreżentaw lis-Soċjetà tagħna fis-seminar "From Compliance to adherence in long term MS Therapies" (Brussel, Ottubru 2004). Rapport dwar dan is-seminar deher fl-ahħar harga tal-Bullettin.



**Dr Norbert Vella,  
Konsulent mediku**

### **3 Attivitajiet Socjali u Edukattivi**

Is-Socjetà tipprowa tlaqqa' lill-membri taghha kważi kull xahar. Il-laqghat isiru nhar ta' Sibt wara nofs in-nhar fil-Hospice Centre, Balzan. Dan iċ-Ċentru huwa ġentilment offrut mill-Management bla ħlas. Saru diversi taħdidiet fuq aspetti differenti tal-kundizzjoni ta' l-MS. Fost il-mistiednin kellna lil Dr Norbert Vella li tkellem fuq l-Rev Fr Bernard Mallia SJ missjonarju fis-Sudan li tkellem dwar l-esperjenza tiegħu.

Il-party tal-Milied sar f' lukanda ewlenija u kien suċċess kbir. Tqassmu rigali sbieħ mill-fondi tas-Socjetà u oħrajn mis-Sur Simon Soler.

### **4. Laqghat importanti**

Matul is-sena 2004 Dr M Zammit u Ms C Carabott attendew regolarmet il-laqghat li jsiru mill-Federazzjoni Għall-Organizzazzjonijiet Persuni b'Disabilità.

Saru diversi laqghat mad-direttur ta' l-MCAST għall-Community Services li wasslu biex f'Marzu saret Maratona tax-Xagħar u Sbuħija. Għal dawn il-laqghat attendew Mr L Agius, Ms R Grech, Ms L Gusman, Mr G Leone Ganado u Mr S Soler.

### **5. Proġett tal-Fiżjoterapija**

Minn Novembru 1999, is-Socjetà bdiet toffri dan is-servizz issussidjat għall-membri taghha bl-MS. Is-servizz fid-djar tal-membri kiber ħafna u qed ikun immexxi minn żewġ fiżjoterapisti. Matul is-sena 2004, kien hemm 17-il membru li ha l-fiżjoterapija u saru 781 sessjoni. Nixtiequ niringrazzjaw lil Ms Patricia O'Brien u Ms Samantha Bonnici tas-servizz tagħhom.

### **6. Proġett tal-Psikoterapija**

Dan is-servizz tal-Psikoterapija lil-membri taghna jinsab fit-tieni sena. Is-servizz jingħata fi grupp u huwa ssussidjat kompletament mis-Socjetà. Nixtiequ niringrazzjaw lil Ms Caroline Mallia tas-servizz taghha.

## 7. Proġett tas-Cyber Café'

Il-Proġett tas-Cyber Café', immexxi mill-voluntiera Polakka Daria Urbanczyk, ġie fi tmiemu din is-sena wara sena ta' taġħlim tal-Kompjuter lill-membri taġħna. L-ghan ta' dan is-servizz kien li persuni bl'MS jkunu jistgħu jikkommunikaw ma' persuni oħra barra minn xtutna permezz tal-kompjuter. Dan il-proġett sar b'kollaborazzjoni mal-European Multiple Sclerosis Platform u l-European Voluntary Service. Ħajr lil Ms Daria Urbanczyk u lir-Razzett tal-Ħbiberija li pprova l-faċilitajiet għal dan il-proġett.

## 8. Trasport

Ħajr lis-sinjur u s-sinjura Joe Tabone talli jieħdu hsieb il-'bookings' tat-trasport għall-membri taġħna għal kull laqgħa li jkollna, kemm fil-Hospice Movement kif ukoll meta nohorgu għal xi attivitajiet soċjali. Dan is-servizz toffrieh is-Soċjetà taġħna.

## 9. Benefatturi

Kellna ħafna benefatturi matul is-sena. Parti minn dawn il-fondi jmorru għas-Servizz tal-Fiżjoterapija u tal-Psikoterapija. Uħud mill-benefatturi huma il-Hospice Movement, HSBC Ltd, Bank of Valletta Ltd, APS Bank, Lombard Bank, Vodafone, Melita Cable, Pricewaterhouse Coopers' Welfare Fund, is-Sur Simon Soler, British Home Stores, Expressions Stationery (Balluta), Institute of Community Services, MCAST, Gauci Stores (B'Kara).

## 10. Gheluq

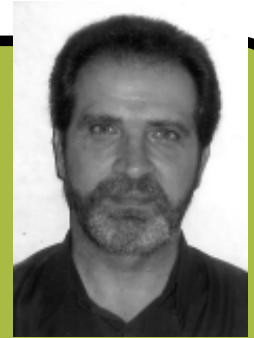
Nixtieq ukoll nappella għall-appoġġ taġħkom lill-membri tal-Kumitat, li jagħmlu xogħolhom b'reqqa u b'dedikazzjoni u jieħdu ħafna mill-ħin liberu taġħhom. Nixtieq niringrazzja ukoll lil dawk il-membri tas-sotto-kumitati li taw sehemhom u taw hinhom biex jgħinu lill-membri bħalhom tas-Soċjetà. Nappella għal iżjed membri li jgħinuna fil-Kumitat u fis-sotto-kumitati sabiex inwasslu servizz aħjar. Niringrazzja wkoll lill-membri kollha tas-Soċjetà li jagħtu sehemhom ukoll mid-dar, anke jekk jaqraw il-Bulletin u ċ-ċirkularijiet li nibgħatulhom, għax b'hekk ikunu qed iżommu kuntatt mas-Soċjetà.



Louise-Anne Gusman, Segretarja

## Editorjal

Minhabba raġunijiet ta' spazju, ma nistax intawwal. Riċentement attendejt għal-laqgħat tal-Bord tal-Federazzjoni Internazzjonali tal-Multiple Sclerosis f'Londra u nnotajt b'sodisfazzjon li l-Federazzjoni qed tagħmel minn kollox sabiex tkun aktar relevanti għall-persuni bl-MS. Minbarra r-riċerka ffinanzjata minnha, il-Federazzjoni għadha kif ippubblikat dokument mill-aktar importanti dwar il-kwalita' ta' hajja għal persuni bl-MS. Barra minn hekk, is-Socjeta' tagħna laqqgħet il-laqgħa generali. Mir-rapport li qed nippubblikaw wiehed jista' jiehu idea tal-hidma tas-Socjeta'. Żgur li bis-sehem tal-membri, din il-hidma tista' tikber hafna aktar u b'hekk inkunu ta' għajnuna akbar għall-membri tagħna. Sahhiet.



Dr M. Zammit

## Serono close to identifying the genes involved in Multiple Sclerosis

Serono, the world's third largest biotechnology company, announced today that researchers at the Serono Genetics Institute (SGI) have achieved a major milestone in identifying and creating a register of genes involved in multiple sclerosis (MS). For the first time in this disease area, researchers at the SGI have identified 80 genes involved in the inflammatory and neuro-degenerative pathways of MS, based on a 40% genome scan comparing the genetic profile of a total of 1,800 people with MS and healthy individuals in different populations. The understanding of the disease genetics in MS will enhance Serono's drug discovery in identifying proteins that can be used either as targets for drug development or directly as therapeutics. In addition, the knowledge of genetics in MS provides a basis for better designing safer and more effective drugs and enabling physicians to address unmet needs and potentially better match treatments to the individual patient. This large-scale association study was performed in a French, Swedish and American population, including a total of 900 people with MS and an equivalent number of healthy individuals.

# Rapport

*Dan li ġej huwa rapport ipprezentat mis-Sur **Kenneth Muscat** tas-Socjetà tagħna fil-Kungress tal-European MS Platform li sar dan l-aħħar f'Bucharest.*

## **Being diagnosed at the age of 22: What does it mean to me?**

I am 38 years old and I have been with MS for the past 15 years. When I had the first symptoms, I was pursuing an M.B.A. in San Francisco, California. My MS condition started when I was sitting for an exam in the spring of 1989. The first symptom I experienced was that I found difficulty in writing, particularly, my c's, my e's, my w's, and u's, the letters that needed curvatures. I thought that this was no big deal. Rather, I thought this was only due to my spending hours on end on the computer. In hindsight, I believed this was the start of the relaxing-remitting type of MS that started to affect me.

In September 1989, I developed numbness (pins and needles) in my right thigh and groin area, which lasted about one month. A few months later the sensory symptoms returned again, in my left thigh, this time, and lasted a few weeks. When walking or having a shower, I used to notice that my thigh was numb – there was no feeling at all. I began to find difficulty in coordinating my right arm movements particularly when combing my hair, shaving, and buttoning my shirts.

During my course in the United States I visited a neurologist but he attributed my symptoms to tension, caused by my studies. Even in Malta, I visited some doctors in the hope of getting to know what I had. They all thought the problem was that of writer's cramp but I had a gut feeling that there was more to it than that. I really wished and hoped that I would find a doctor holding a magic wand and

explaining the actual deficit in me.

It so happened that in 1995, I was visiting my sister in the United States and an exacerbation suddenly took place. My right leg was giving way causing me to limp while walking. This symptom caused me to trip more often. The same thing occurred again in summer 2002. Following a hospital visit for a check-up and an MRI, I was diagnosed with MS. Finally, at long last, after so many years in the dark, I was starting to see some light at the end of this tunnel. In the sense that now, I knew what I had and what I had to cope with. The word MS was new to me. When the doctor mentioned you have multiple sclerosis, the word “multiple” scared me. Many thoughts came racing through my mind. How is it going to affect my work, how am I going to inform my employer of the condition, will I still be able to work? What about my future? Will my parents and my partner accept my condition? Most of all, will my family support me?

Ever since I first felt the first symptoms in 1989, my handwriting had changed. The in-coordination when using my right hand has persisted and progressively gotten worse. So much so that at present my handwriting is almost illegible. When necessary, I now make use of my left hand to write, and the computer also.

These symptoms through the years have forced me to curtail my participation in sports. I used to like going for walks, but now, when I go, it is not for long distances. I used to love dancing too, but I cannot do that now. So instead, I have tried to find other things to do. These include swimming and visiting a gym.

Through the years I've had MS, I have noticed that the best way to face this condition has been to think positive and confront it. Whilst initially experiencing anger, frustration, and bitterness, and even jealousy towards others, over time, I began to slowly understand that these adverse emotions were not helping me in reducing the stress and tension. On the other hand, they would increase the possibility of more exacerbations. A violent cycle of events I didn't want to face. So my attitude began to turn to one of slow acceptance of the situation and better understanding of my condition. I tried to relate better with others, especially my family and my peers who are afflicted with MS.

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*(Rapport iehor fil-harga li jmiss)*