

Matul ix-xhur shan tas-sajf, is-Socjetà taghna ma waqqfixx l-attivitajiet taghha. Fit-18 ta' Ġunju għadd sabih ta' membri ltaqgħu f'wahda mill-lukandi ewlenin fejn hadu pizza u għaddeu lejla mill-isbaħ fil-kumpanija ta' xulxin. Fit-30 ta' Lulju, Fr Benjamin Galea qaddes quddiesa għall-membri fil-Hospice Centre. Il-membri apprezzaw hafna l-mod kif Fr Benjamin mexxa din l-attività.

Dawra mal-port ta' Marsamxett: Success tal-fund-raising event

Nhar is-Sibt 23 ta' Lulju, hbieb tas-Socjetà taghna mmexxija mis-Sur Simon Soler, ghogobhom jorganizzaw avveniment pjačevoli u edukativ bl-iskop li jingabru fondi għas-servizzi ta' fizjoterapija u psikoterapija li s-Socjetà toffri lill-membri. Is-Sur Soler u l-hbieb tiegħu gentilment offrew l-opri tal-baħar tagħhom sabiex jieħdu lill-pubbliku dawra mal-port tant sabih u storiku ta' Marsamxett. B'kollox kellna erba' opri: dgħajsa tal-qlugh, żewg motor boats u speed boat. Il-ġurnata veru rnexxiet għax kemm it-temp kif ukoll il-baħar kienu ideali. Eżatt mat-tokk tad-disgħa tfačča l-ewwel grupp ta' xi għoxrin ruħ, grupp ta' Scouts mit-truppa tan-Naxxar, lebsin l-uniformi sabiħa tagħhom.



Ms Kate Gonzi flimkien mal-president tas-Socjetà Leslie Agius u s-sinjura tiegħu

Ftit wara giet is-Sinjura Kate Gonzi, mart il-Prim Ministru li, minkejja l-programm intensiv li kellha, ġentilment sabet il-hin sabiex tappoġġja l-attività taghna u anke tagħmel kelmtejn interessanti fuq il-volontarjat lil dawk prezenti. Mrs Gonzi heġġet liż-żgħażaġh biex jimpenjaw ruhhom serjament fil-volontarjat u biex ma jaqtgħux qalbhom jekk l-isforzi tagħhom mhux dejjem isibu l-appoġġ mixtieq. Il-volontarjat juri kemm huma ġeneruzi l-persuni li joffru x-xogħol u l-hin liberu tagħhom għal haddiehor u huwa l-ahjar taħriġ għaż-żgħażaġh għal meta jikbru.



Prezenti wkoll għall-okkażżjoni kien hemm il-Viċi-sindku tal-Gżira s-sur Victor Rutter. Il-President tas-Socjetà, Leslie Agius u s-sinjura tiegħu Vicky, flimkien mat-Teżorier, Godfrey Leone Ganado, laqgħu lill-mistiedna speċjali.



Mrs Gonzi mbaġhad marret ghal dawra qasira fil-port fid-dghajsa tal-qlugh. Minn kummenti li hadna wara l-avveniment jidher li kulmin ha sehem kien kuntent b'din l-esperjenza li fethitilhom ghajnejhom ghas-sbuhija tal-portijiet taghna u tal-wirt storiku ta' pajjizna. Ghas-Socjeta il-gbir ta' fondi mid-donazzjonijiet tal-pubbliku kien ukoll soddisfacenti hafna u se jghin mhux fit fil-hidma taghna.

Minn qalbna niringrazzjaw lil daww kollha li b'xi mod jew iehor gheni biex ghamlu success minn din l-inizjattiva, speċjalment lil Simon u lil shabu li offrew id-dghajjes taghhom u li hadmu bla waqfien il-gurnata kollha.

Editorjal

Il-kundizzjoni tal-MS, minbarra li taffettwa fizikament lill-persuna milquta biha, taffetwalha wkoll il-kwalita ta' hajja taghha. F'April li ghadda l-Federazzjoni Internazzjonali tal-MS xandret ghaxar principji li, jekk l-awtoritajiet koncernati u kulmin ghandu x'jaqsam ma' persuni bl-MS, inkluzi l-ghaqdiet nazzjonali tal-MS, jaddottawhom bhala pjan ta' hidma ghall-gejjieni, il-kwalita ta' hajja tal-pazzjenti bl-MS ma tmurx lura u l-htigijiet baziċi taghhom ikunu mharsa. L-ghaxar principji jikkoncernaw:

1. sehem il-persuni bl-MS fid-deċizjonijiet li jittiehdu dwarhom
2. il-kura medika
3. kura fit-tul
4. promozzjoni tas-sahha u prevenzjoni
5. support lill-membri tal-familja
6. it-trasport
7. ix-xoghol u l-hidma volontarja
8. beneficċji ta' dizabilita u ghajnuna fi flus
9. l-edukazzjoni
10. housing u accessibilita.

F'din il-harga u fil-hargiet li gejjin tal-Bullettin, se naghtukom taghrif dwar dawn il-principji. Min ghandu l-internet, jista' jaqra dwarhom f'dan l-indirizz: http://www.msif.org/en/publications/quality_of_life_principles/index.html

It-taghrif ghandu qawwa kbira u jekk irridu ntejbu l-qaghda taghna l-pazzjenti u l-familjari, jehtieg li ninfirmaw irwiehna sewwa.

Membru tas-Socjetà taghna fost il-kelliema ewlenin fil-Kungress tal-EMSP (Bukarest, Rumanija – Mejju 2005)

Living with MS - My personal dream about my future

When I was told that I have MS, I got apprehensive and confused, particularly about my future. Multiple Sclerosis has changed my life. The way in which MS affects a person with the disease has a major impact on his or her interaction with the people encountered in day-to-day activities, at home and at work.

In this regard, I believe communication is important in helping my family members cope with changes in my lifestyle, due to my MS. Being an introvert in nature, it will be more important for me, as the person with MS, to talk about what is different in life, what I am no longer able to do, what I would like to strive to achieve one day, and how to discuss with members of my family how these things will get done. I think that some dialogue and sharing would help family members in general, understand what is going on.

Furthermore, a dream I'd like to achieve is to succeed in my professional banking career. Nonetheless, I have gradually discovered that my medical condition and the misunderstandings by people, of what I have, have created more difficulty in my moving forward in my job. I have begun to accept that if my superiors were to add more strenuous activities to my present job, there might arise the need or the necessity for me to seek employment elsewhere.

Another dream I would like to divulge with you is that of sharing my life with a partner who is caring and understanding, especially in my present medical condition. I believe that if my partner and I are able to speak openly and honestly with each other, I'll probably find that we would be brought closer together and be able to help each other through difficult times.

At the end of it all, my basic goal to achieve my dreams is to make my day fruitful and worthwhile. I want to start living for today. I still intend to plan for tomorrow but it

F'Mejju ta' din is-sena, il-European Multiple Sclerosis Platform (EMSP) kellha l-laqgħa annwali tagħha f' Bukarest, fir-Runamija. L-EMSP thaddan soċjetajiet Ewropej tal-MS, fosthom is-Socjetà tagħna li hija membru attiv fi hdan din l-għaqda. Il-laqgħa tax-xahar li għadda kienet dedikata għaz-żgħazagħ milqutin bl-MS u ġew mistiedna tliet żgħazagħ minn fost l-għaqdiet Ewropej sabiex jitekellmu dwar kif huma rreaġixxew għall-aħbar li kellhom l-MS u dwar kif l-MS affettwalhom hajjithom. Kien unur kbir għas-Socjetà tagħna li kienet magħzula biex tinnomina wiehed minn dawn it-tliet kelliema. Is-Socjetà nnominat lil Kenneth Muscat li ilu membru attiv sa mill-bidu tas-Socjetà. Kenneth tkellem darbtejn f'dan il-kungress u ntlaga' tajjeb ħafna. Fil-harġa tal-Bullettin ta' Mejjju ġibna l-ewwel diskors ta' Kenneth. Illum qed inxandru t-tieni intervent tiegħu.

will not help if I continue to grieve for yesterday. I need to be positive and begin to set realistic short, medium, and long-term goals. I guess that by having some objective it will give me something to look forward to and put some structure in my life.

Dear friends, one last point I want to make is this. I have found that having MS does not mean my life has come to a stop. It has meant that I have had to adapt to a different lifestyle that has suited my capabilities and possibilities. But the golden rule I have found, has been, to maintain in me, as often as I can, a positive attitude towards the various circumstances I encounter each day.

Above all, once I begin to accept that I am still valuable as a person even if my body does not always function the way I would like, I will then start to gain control of my own life and destiny again. As I confront the challenges of my everyday life with MS, and learn alternative ways to do things, I have begun to identify some strengths and talents I never knew I had. Since I have been forced to give up on certain activities that have been important in my life, like playing soccer and photography, I have been trying to experiment with others that may turn out to be equally satisfying. I am trying to look for ways within myself which MS cannot touch. For instance, writing an article for a newspaper/journal, swimming, listening to music or watch a movie. Well it is not always possible to do these things since at times, MS presents stressful situations.

I would like to experience freedom to grow as a person and always try to move on. As much as possible, I will try not to let M.S. curtail who I am or what I want to do with myself.

Kenneth Muscat

Kwalità Ta' Hajja Ahjar

Dan l-artiklu hu mislut mill-pubblikazzjoni 'Principji sabiex titjieb il-kwalità tal-hajja ta' persuni bl-MS' mahruġ mill-Multiple Sclerosis International Federation. Traduzzjoni mill-Ingiliz ta' Rose Grech.

Il-Multiple Sclerosis [M.S.] hi marda kronika li thalli impatt kbir fuq il-kwalità ta' hajja ta' l-individwu. Ghalhekk hu importanti li jitfassal programm u servizzi li jassiguraw li dawk li jbatu b'din il-marda jkunu indipendenti biex kemm jista' jkun ikollhom kontroll fuq hajjithom.

Fil-passat hafna servizzi tas-sahha ibbazaw aktar fuq it-trattament tas-sintomi u l-kura tal-marda minflok ma taw aktar attenzjoni lill-persuna tal-marid. Fortunatament, illum is-servizz tas-sahha hu hafna aktar mixhut fuq il-bzonnijiet tal-pazzjent bhal, per eżempju, l-indipendenza tieghu, l-impjeg, l-edukazzjoni u aspetti ohrajn li ghandhom effett fuq kwalità ta' hajja. Bis-sehem ta' hmistax-il Ċentru mifruxa mad-dinja, l-Organizzazzjoni Dinija tas-Sahha żviluppat qafas ta' rakkomandazzjonijiet dwar il-kwalità ta' hajja. Bi kwalità tal-hajja nifhmu l-mod li bih kull individwu jara lulu nnifsu u l-pożizzjoni tieghu fil-kuntest tas-soċjetà li jghix fiha u tal-ambizzjonijiet u l-interessi tieghu. Dawn il-principji jipprovdu bazi tajba ghal soċjetajiet Nazzjonali ta' l-Multiple Sclerosis, sabiex dawn iżviluppaw u jwettqu pjani biex itejbu l-kwalità ta' hajja ghal dawk milquta minn din il-marda li tibqa' mieghek hajtek kollha.

Tghidilna J.K.Rowling, il-kittieba famuża tal-kotba Harry Potter, li ommha kellha hamsa u tletin sena meta qalulha li kellha l-M.S. Ghall-ewwel ippruvat tghix hajja normali; kienet taqra hafna fuq din il-kundizzjoni taghha iżda qatt ma basret kemm kienet se tkun progressiva fuqha. F'dawk l-ghaxar snin li ommha damet tbatu bl-M.S. kellha x-xorti rat fizjoterapista ghaxar darbiet. Kellha thalli x-xoghol hesrem, ghajnuna fid-dar ma kellhiex, kellha thalli d-delizzi taghha bhall-ghawm, xoghol fil-ġnien, mixi u qari. Sahansitra giet fi stat li kellha titkaxkar biex titla' t-taraġ. Dak iż-żmien, is-servizz tas-sahha ftit li xejn seta' jipprovdi ghajnuna. Izda ma kienx biss il-progress imghagġel tal-marda li affetwat lilha u lill-familja kollha. L-iżjed li affettwaha kien pjuttost it-telf tal-kwalità ta' hajja li kellha, ta' l-istima taghha nfisha, ta' l-indipendenza taghha u l-hsieb li kienet ta' piż ghall-familja.

Il-kwalità ta' hajja ghall-persuni bl-M.S. hi xi haġa li wiehed irid jibqa' jiggieled ghaliha fil-pajjizi kollha. Sabiex dan isehh, ghandna bżonn f'idejna l-ghodda

mehtieġa. Hekk tkompli tghid J.K.Rowling li illum hi il-Patrana tas-Socjeta' ta' l-M.S. ta' Scotland.

Multiple Sclerosis hi marda kronika u kumplikata li taffettwa kwazi 2.5 miljun persuna. Ghalkemm l-impatt tal-marda tvarja minn persuna ghal ohra, is-sintomi komuni jinkludu, fost l-ohrajn, ghejja, infezzjoni fil-bużżieqa tal-awrina, problemi fil-vista, tnemnim, u nuqqas ta' koordinazzjoni. Fost il-problemi li persuni bl-M.S. jiltaqghu magghom hemm diffikultajiet biex wiehed jiekol, jinhasel, jilbes, johrog ghax xoghol, jaghmel xoghol fid-dar, problemi fil-mixi, ugiegh u depressjoni.

B'rizultat ta' dawn is-sintomi, din il-marda thalli effett qawwi fuq il-kwalita' ta' hajja tal-individwu. Bejn l-istress u d-dizabilita' li jikkawzaw dawn is-sintomi, hafna drabi wiehed ikollu jitlaq l-impjeg u jisfa jiddependi fuq niesu jew fuq is-servizzi soċjali ghall-finanzi u s-sapport.

Wiehed irid dejjem izomm f'mohhu li l-ghan ahhari hu l-kura u l-fejqan mill-M.S. Izda sakemm din tinstab, hu importanti li nahdmu biex nirrangaw jew intejbu l-kwalita' ta' hajja ghal nies li jbatu bl-M.S., permezz tal-principji li fasslet ghalina l-Multiple Sclerosis International Federation. Dwar dawn il-principji nitkellmu fil-harga li jmiss.

Multiple Sclerosis

MS is a condition about which one does not hear very often in Malta. This is mainly due to the low incidence of the disease in our islands, an incidence which is significantly lower than those of nearby Sicilian towns such as Enna, Agrigento, Acireale and Caltanissetta and, indeed, of the rest of Europe. Yet MS is the most common non-traumatic neurological disease in young adults in the world and afflicts some 2.5 million persons worldwide.

Until the advent of MRI diagnosis of MS was very difficult and several cases of misdiagnosis are recorded. In a study of MS in Malta carried out in 1978 by Drs Dean and Elian, 14 persons with MS were identified. A second survey in 1999 by the same doctors, in conjunction with Maltese consultant neurologists, showed a significant increase but the prevalence in Malta remains very low. According to the records of the Multiple Sclerosis Society of Malta the current number of confirmed cases hovers around the figure of 100.

As yet there is neither a cure for, nor a certainty as to the causes of MS. MS is an inflammatory demyelinating condition in which the myelin is attacked by the body's immune system itself. Myelin is the fatty substance insulating the nerve fibres, thus ensuring that messages from the brain are transmitted speedily and efficiently to the rest of the body. In MS, the loss of myelin causes a disruption in the ability of nerves to conduct electrical impulses to and from the brain with the result that the different parts of the body fail to react to stimuli from the brain. The sites where myelin is lost appear as hardened scar areas (plaques) and they appear at different times and in different areas of the brain and spinal cord. Researchers do not know what triggers the immune system to attack myelin; one theory is that a dormant virus in the body (e.g. measles or herpes) may act as a trigger by activating the white blood cells, which enter the brain by rendering vulnerable the brain's defence mechanisms. Once inside the brain these cells activate other elements of the immune system in such a way that they attack and destroy myelin. The most common symptoms of MS are blurred vision, numbness or tingling of the limbs, fatigue and problems with coordination. There are four types of MS, and the relapsing forms are the most common.

There is considerable research all over the world about causes of and cures for MS. In their report following the 1999 survey, Drs Dean and Elian suggested that the reason for the low prevalence of MS in Malta could be explained by environmental factors and, more importantly, by a different genetic make up of the Maltese people to the rest of Europe. Indeed, Dean and Elian suggest that Malta offers a unique opportunity for researchers to ascertain the relative importance of genetic and environmental factors responsible for MS.

Very recently a major milestone was reached through the identification of 80 genes involved in MS. This is a significant step forward in building a complete inventory of genes involved in MS. The completion in 2006 of the MS Whole Genome Scan will lead to a comprehensive catalogue of potential MS drug targets, thus providing the basis for a future development of innovative MS therapies. The understanding of the disease's genetics will enhance the possibility of 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 the better designing of safer and more effective drugs and enabling physicians to address unmet needs and potentially match treatments to individual patients.

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