

II-Logġob Paralimpiku – Atení 2004



Wara s-suċċess kbir tal-logġob Olimpiku f'Awissu li għadda l-ewwa Atení, f'dawn il-jiem, sa tmiem Settembru, qiegħed isir il-logġob imsejjaġ paralimpiku, jiġi f'ierri logġob li jieđdu sehem fih atleti b'diŷabbiltà. It-22 sport differenti f'dan il-logġob huma: qaws, atletika, basketball, basketball fil-wheelchair bođđi, ġikliŷmu fuq it-triq u fit-trekk, ŷiemel, futbol (5-a-side u 7-a-side), goalball, l-udo, powerlifting, ibburđjar, sparar, għawm, table tennis, volleyball, dwell fil-wheelchair, rugby fil-wheelchair.

Kien fl-1948 li Sir Ludwig Guttmann organizza kompetizzjoni sportiva fi Stoke Mandeville, fl-Ingilterra għal veterani tat-Tieni Gwerra Dinjija li kienu ndarbu fix-xewka ta' daharhom. Erba' snin wara, kompetituri mill-Olanda ingħaqdu fil-logġob u b'hekk taw bidu għall-moviment internazzjonali msejjaġ illum il-Moviment Paralimpiku. Kien fl-1960, l-ewwa Ruma, li l-logġob saru fuq il-mudell ta' dawk olimpiđi. Fl-1976, fl-Ilŷvezja, l-eww organizzati l-ewwel logġob paralimpiđi tax-xitwa.

Illum hemm sitt gruppi ta' diŷabbiltà li jieđu sehem f'dan il-logġob. L-għan ta' dan il-logġob huwa li wieđed jisđaq fuq il-kisbiet atletiđi tal-partedipanti u mhux fuq id-diŷabbiltà tagħhom. Il-partedipazzjoni f'dawn il-logġob tiŷdied minn edizzjoni għall-ođra. Hekk naraw li minn 400 partedipant fl-edizzjoni ta' l-1960 f'Ruma, f'dik ta' Sydney tas-sena 2000 óadu sehem 3843 atleta minn 122 pajjiŷ.

II-Kwalità tal-Óajja gÓall-Persuni bl-MS

Il-Federazzjoni Internazzjonali tal-MS (MSIF) gÓadha kif nediet proġett Ġdid li gÓandu jĠib 'il quddiem il-kwalità tal-Óajja gÓal persuni bl-MS. Il-proġett gÓadu fil-faġi ta' tÓejjija u huwa maÓsub li jkun varat f'April 2005. Il-Ósieb huwa li l-proġett jiŰviluppa gÓadd ta' prinċipji internazzjonali dwar il-kwalità tal-Óajja sabiex dawn, imbagÓad ikun adottati sew mis-soċjetajiet nazzjonali kif ukoll mill-MSIF. Il-Federazzjoni Internazzjonali tal-MS hija konxja Óafna tad-diffikultajiet quddiem proġett bÓal dan. Dan minÓabba d-differenzi kbar li jeŰistu bejn il-livelli tal-Óajja fil-pajjiŰi differenti, u gÓalhekk is-servizzi offruti lil persuni bl-MS mhumiex kullimkien l-istess. Kien minÓabba f'hekk li l-proġett kellu jillimita ruÓu gÓall-aspetti Ġenerali tal-kwalità tal-Óajja.

Skond tagÓrif miksub s'issa, il-prinċipji ewlenin se jkunu dawn:

1. L-Indipendenza tal-pazzjent u l-jedd li jiddeĊiedu gÓalihon infushom.
2. Il-Kura Medika.
3. Il-Kura Soċjali.
4. Promozzjoni tas-SaÓÓa u l-Prevenzjoni
5. Sapport gÓall-Membri tal-Familja
6. It-Trasport.
7. Ix-XogÓol u l-Attivitajiet Voluntarji.
8. BenefiĊċji tad-DiŰabilità u GÓajnuna bi Flus.
9. L-Edukazzjoni.
10. Id-Djar u l-AĊĊessibilità ta' Bini fil-Komunità.

L-MSIF ikkommissjonat lir-Research Triangle Institute Intrenational sabiex jiŰviluppa dan il-proġett. Is-siwi ta' dan il-proġett huwa li bis-saÓÓa tiegÓu is-soċjetajiet nazzjonali, u l-gÓaqda tagÓna hija waÓda minnhom, ikunu jistgÓu jippjanaw l-istrateĠiji u l-inizjattivi tagÓhom u jiŰviluppaw is-servizzi u l-programmi ta' sapport skond il-prinċipji mfasla f'dan il-proġett. Fuq livell internazzjonali, dan il-proġett jagÓti l-mezz lill-MSIF biex jitkellem f'isem il-persuni milqutin bl-MS u f'isem is-soċjetajiet nazzjonali fil-kampanji tiegÓu gÓal servizzi aÓjar lill-persuni bl-MS. Il-Federazzjoni Internazzjonali tal-MS irĊeviet gÓotja ta' flus mill-kumpanija medika Biogen biex tkun tista' tidÓol gÓal dan il-proġett.



MS in Focus – Nri 3 u 4

Il-Federazzjoni Internazzjonali tal-MS għadha ixxandar il-Ĵurnal MS in Focus li jiktbu fih bosta esperti dinjin fil-qasam ta' l-MS. L-għadd numru 3 jittratta b'mod partikulari dwar aspetti familjari. Min-oħra s-suġġett magħodd, dan l-għadd għandu jkun ta' interess kbir mhux biss għal persuni bl-MS, iŵda għall-membri kollha tal-familja tagħhom. Fih taqraw artkli dwar:

- X'hemm fl-MS li jagħmilha marda "tal-familja"?
- Kif t-oġġar lil uliedek jikkellmu dwar l-MS.
- Kif tiegħu oħsieb dawk li jiegħdu oħsieb persuni bl-MS?
- Nisa tqal li jbatu bl-MS.
- It-tfal ukoll jistgħu jintlaqtu bl-MS.

(Ikompili fil-paġna li jmiss)

Is-sit tal-MSIF fil-Web:

Jekk fid-dar hemm kompjuter imqabbad mal-internet, persuni bl-MS u l-familjari tagħhom għandhom l-oportunità li jinfurmaw irwiegħom aktar dwar l-MS billi jidgħu fis-sit tal-MSIF (<http://www.msif.org>). Fih isibu seba' taqsimiet kbar, litteralment mimlija daqs bajda b'taġoġrif mill-aktar interessanti u meoħtieġ. Dawn

- Aħbarijiet mix-xena internazzjonali
- Sintomi u trattament
- Riġerka
- Taġoġrif dwar l-MSIF
- Il-Marda MS
- Persuni bl-MS
- Pubblikazzjonijiet

Tistgħu tirreġistraw bla oħlas b'ala "users" ta' dan is-sit u tibdew tikkomunikaw ma' persuni bl-MS b'alkom. Tkunu tistgħu ukoll taqraw profili dwar persuni bl-MS li jirakkuntaw l-esperjenza tagħhom bl-MS u, jekk tridu, tistgħu tibagħtu l-esperjenza personali tagħom. B'hekk tinoħloq tassew komunità dinjija ta' nies bl-MS.

Minflok noqogħdu biss fuq dak li nisimgħu, ikun oħafna aħjar jekk immorru f'ras il-għajn u ninfurmaw irwiegħna direttament mingħand l-esperti fil-qasam tal-MS.

Ir-raba' edizzjoni tal-MS in Focus tittratta dwar il-qasam psikoloġiku. Fih taqraw dwar:

- Introduzzjoni għal kwistjonijiet emozjonali li ġejjin mill-MS.
- Id-dipressjoni u l-MS.
- Problemi ta' konjizzjoni fil-ġajja ta' kuljum.
- Mezzi oħra kif tpatti għall-problemi ta' memorja.
- Intervista

Idoal issa fis-sit tal-MSIF (<http://www.msif.org>) u kklikkja fuq "Publications". Jekk trid tista' taqra l-artikli minn fuq il-monitor, jew inkella tniġġel l-artikli billi tistampahom u taqrahom meta u fejn trid.

Chairperson Ġdid għall-Federazzjoni Dinjija tal-MS

Is-Sinjura Sarah Phillips, chairperson tas-Soċjetà Ingliża tal-MS għadha kif inoatret chairperson tal-Federazzjoni dinjija. Is-sinjura Phillips, li għandha 61 sena, kienet kowċ tat-tennis u fl-1981 saret taf li kellha l-MS. Hija u ūewġha Peter għandhom ūewġt itfal.



From the *Dictionary of Multiple Sclerosis**

Primary Progressive MS (PP MS): Disease course characterized by progressive deterioration from the onset of disease, without clear-cut relapses or remissions, but with occasional plateaux and temporary minor improvements. Approximately 10% to 25% of patients experience progression from onset.

Primary progressive MS, definite: MS with solely progressive course for at least one year, positive cerebrospinal fluid and either positive MRI evidence, or equivocal MRI evidence and a delayed visual evoked potential.

Primary progressive MS, possible: Patients suspected to have PP MS with clinical progression for at least one year and equivocal MRI evidence or delayed visual evoked potential.

Primary progressive MS, probable: Patients suspected to have PP MS with either (a) clinical progression for at least one year, positive cerebrospinal fluid and equivocal MRI evidence, or delayed visual evoked potential, or (b) clinical progression for at least one year, positive MRI or equivocal MRI evidence and a delayed visual evoked potential (cerebrospinal fluid evidence either unavailable or negative).

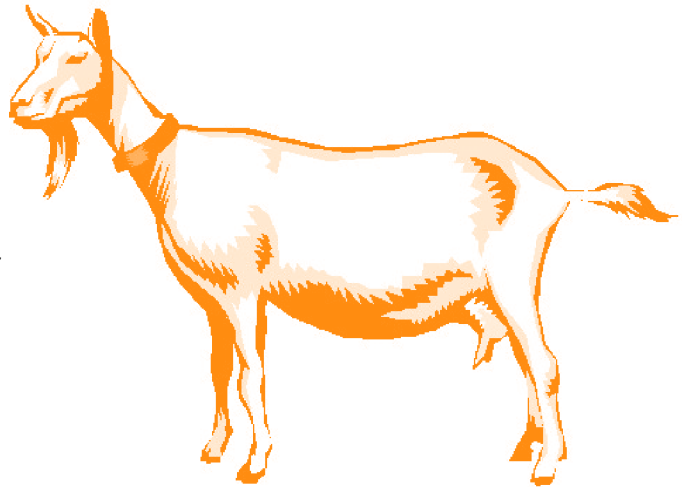
* Lance D. Blumhardt (Editor-in-Chief), Taylor & Francis Group. 2004.

Tama fis-serum tal-mogóŭa góal persuni bl-MS

Skond il-London Times tal-25 ta' Jannar, persuni bl-MS kellhom titjib kbir fil-kundizzjoni tagóhom wara li óadu bi tlaqqmu darba fil-Íimgóa b'injezzjoni magómula mis-serum tal-mogóŭa (caprivax). Uóud minn dawn il-pazzjenti rrapportaw li qegódin jimxu mingóajr bastun, filwaqt li oórajn qalu li l-vista íiet góalli kienet. Minn 130 persuna li óadu sehem f'dan l-esperiment, 85% minnhom stqarru li óassewhom óafna aójar minn qabel, mingóajr ma batew minn side effects. Persuna fosthom qalet li tóossha 500% aójar, li beda jimxi mili s0a0 mingóajr bastun, u li jóossu óafna aktar b'saóótu. Fost dawk li tlaqqmu bil-capriax hemm ukoll il-kantant Alan Osmond. It-team ta' xjentisti nvoluti fl-iúvilupp ta' din id-droga huwa mmexxi mill-Professor Angus Dalgleish, onkologu f'St. George's hospital, Tooting, south London. Dawn ix-xjentisti jaósbu li dan it-trattament jista' jwassal góal titjib fit-tul.

L-injezzjoni hija magómula minn serum safi ta' mogóoú immunizzat li jiproduđu antibodies. Dan il-óin góaddejjin tliet provi kliniđi separatament. Aspett poúittiv ieóor dwar din id-droga huwa l-fatt li n-nefqa meótieía góall-iúvilupp tagóha hija waóda óafna anqas minn drogi oóra.

Skond it-tabib tal-familja David Maizels, minn Chiselhurst f'Kent, ir-riúultati poúittivi minn din id-droga m'humiex íejjin minn l-effett ta' placebo u t-titjib fil-pazzjenti huwa sostenut u ikwaíi mingóajr side effects. Huwa rrapporta li, xi drabi, ir-riúultati huma impressjonanti. Il-kantant Alan Osmond jisóaq li "... l-aktar importanti huwa li tóares lejn l-affarijiet b'mod poúittiv. Góaliex mhux il-marda li tkissrek, iúda n-nuqqas ta' tama!'



Summary: According to the London Times of January 25th, "Patients suffering from multiple sclerosis (MS) ... have experienced dramatic improvements in their condition after taking part in trials of a drug derived from goat serum. Some have reported being able to cast aside their walking sticks and walk for miles, or of regaining their vision or finding they can again use their limbs after years when any movement was agony. Of the 130 patients on the trial, 85% reported big improvements with no side effects." The new treatment is being pioneered by a team of scientists and doctors led by Professor Angus Dalgleish, an oncologist based at St Georges's hospital, Tooting, south London, who believes it will at worst provide a highly effective subjective treatment for MS sufferers, but may lead to a long-term improvement. (Source: ThisIsMs – an unbiased multiple sclerosis community <http://www.thisisms.com>)

Editorjal

Nittama li qegħdin issibu enerġija biġġejjed biex, b'xi mod jew ieħor, jirnexxielkom tegħlbu s-solana u l-umdità tal-jiem tas-sajf. Din hi parti mit-taqbida msejġa "Oajja ta' kuljum". F'dan l-għadd tal-bullettin tas-Soċjetà tagħna ssibu tagħrif dwar il-Logħob Paralimpiku li fih jieħdu sehem atleti b'bosta forom ta' diġabilità. Is-sabiħ ta' dan il-logħob huwa li l-atleti juru lilhom infushom, u lid-dinja, li minkejja d-diffikultajiet kbar li jinsabu fihom, huma xorta waħda lesti jilqgħu l-isfida tal-Oajja. Huma b'ollikieku jisfidaw id-diġabilità tagħhom u juruha li kapaċi jaqblu d-diffikultajiet li f'ib magħha u jilqu għanijiet li oħadd ma kien jobsor li jilquhom. Mela jixraq li niftakru li dan il-logħob, barra li jisdaq fuq il-kisbiet atletiċi tal-partecipanti u mhux fuq id-diġabbiltà tagħhom, għandu jiswa ta' tagħlima kbira, Għandu jfakkar lil persuni b'diġabilità, hi x'inhil-għamla tad-diġabilità tagħhom, li jistgħu jagħmlu xi oħra aktar b'ojjithom, u li f'ewwa fihom għad hemm oħra aktar enerġija milli qatt basru. Il-Logħob Paralimpiku, mela, if'ib miegħu messa f' kbar ta' ottimiżmu. Sfortunatament, mhux dejjem huwa possibbli li wieħed isegwi dan il-Logħob għaliex l-istazzjonijiet tat-televiżjoni ftit li xejn iħallu spazju għalih. Dan juri li s-soċjetajiet support uviluppanti għadhom ma uviluppawx biġġejjed kuxjenza lejn il-persuni b'diġabilità. Għalkemm forsi ma nammettuhix, nibla' li f'dawn is-soċjetajiet għad hemm min iħossu skomdu meta jara d-diġabilità u jippreferi jara biss il-logħob Olimpiku bl-ispettaklu mill-aqwa li jf'ib miegħu. Iħda jekk wieħed jieqaf jaħseb ftit, ma jdumx ma jintebaħ li, għalkemm l-atleti olimpiċi jistħoqqilhom kull tifħir, madankollu l-atleti diġabbli tixirqilhom kull ammirazzjoni għaliex huma f'kategorija għalihom ... fil-kategorija ta' l-eroj.



Websites Importanti

www.msif.org

www.msmalta.org.mt (il-website tas-Soċjetà ta'Ena)

www.nationalmssociety.org

www.mssociety.org.uk

www.ms-gateway.de

www.ms-care.com

Memory problems?

Don't worry! You can do a lot about it.

- Keep a daily diary or notebook. Write down all appointments, reminders, and lists of things to do in one place. Tick things off once they are done. Get into the habit of referring to this diary routinely, perhaps at the same time each morning and again in the evening for tomorrow's schedule;
- Post a large family calendar in a prominent place, maybe the refrigerator door;
- Use a wristwatch with an alarm, and set it to remind you of events. People who must take medication at certain intervals find this especially useful;
- Electronic gadgets like personal digital organisers are effective for lists, agendas, important phone numbers, and addresses. Or try other organisational tools such as index cards, a portable computer, or using the "reminder" function of your mobile phone;
- Place reminder notes in useful locations around the house or work place;
- Keep important things in a designated place. Keep your daily diary on your night table or next to the phone, your keys in a particular drawer or on a hook near the door. Being consistent in your routine will make it easier to remember where things are;
- Design a master shopping list, with all the items you normally need, and make multiple copies. Before going out to shop, review the list and check off the items you've run out of;
- Try to stay calm when memory fails.



(Adapted from MS in Focus (n. 4). The article is based on MS and the Mind - Memory and Problem Solving, by Martha Jablow, National MS Society, USA)

The Winner of the Nicholson Award for International Caregiver of the Year 2004

The Persons with MS Advisory Group within the MSIF have identified the winner of the Nicholson Award for the International Caregiver of the Year 2004. Alan Lindsley from the UK has been honoured with this award. Alan is 68 years old and cares for his wife Joan who has had MS for 35 years. Joan has been a wheelchair user for the past 20 years. They have two children and four grandchildren. Alan worked in the motor trade for 47 years and retired in 1997. He worked full-time up to the age of 60, continued to care for his wife Joan, and also found time to work as a volunteer in the demanding roles outlined below. Alan was a Trustee on the UK MS Society Board from 1987 - 1996, Chairman of the Northern Association and then of North of England Region, as well as Chairman of the Sunderland branch for 21 years. In his role as a regional volunteer, Alan makes a point of visiting each branch regularly, and has supported branches facing difficulties on many occasions. He also represents people with MS and carers on a number of committees within the local health and social care sector and is seen by senior health and social care professionals as the voice of people with MS and carers within the local area. His success at representing their needs is reflected in the high quality and level of services within Sunderland.

Alan is the sort of person who does not like to be in the limelight but has worked tirelessly in the background, making sure that people without the support of carers, were supported and helped in any way needed.

The Nicholson Award for International Caregiver of the Year is made possible by a special grant from David L. Torrey of the MS Society of Canada.

Previous winners of the Nicholson Award

| | | | | | |
|------|---------------------------|--------------------|------|---------------|--------------|
| 2003 | Skaidrite Beitlere | Latvia | 1998 | Bente Nielsen | Denmark |
| 2002 | Jon Ferguson | Australia | 1997 | Josy Baumann | Switzerland |
| 2001 | Ion Gîda | Romania | 1996 | Joan Dartnell | Australia |
| 2000 | <i>Cor de Wilde</i> | <i>Netherlands</i> | 1995 | Ewa Marszal | Poland |
| 1999 | <i>Helen Jean Mortson</i> | <i>Canada</i> | 1994 | Harry Bell | South Africa |

For further information on the Nicholson Award please contact Paul Rompani, International Development Manager, at MSIF, 3rd Floor, Skyline House, 200 Union Street, London, SE1 OLX, UK. Tel: +44 (0) 20 7620 1911, Fax: +44 (0) 20 7620 1922 or email paul@msif.org.

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