

# BULLETIN

..... • lehen il-multiple sclerosis society ta' malta •

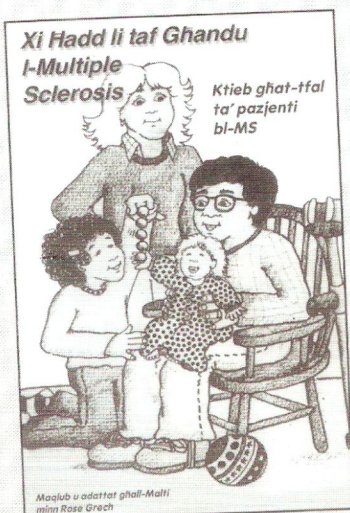
## Editorjal

by Kenneth Muscat

It has been some time since our last communication and I hope that we are all in good spirits now that Spring is in the Air. For me Spring is a wonderful season and it gives me a sense of good feeling, no matter how much our MS condition tends to put us down a bit, and makes us feel weary and tired. We should try and instil a sense of positive attitude. If today we are feeling a bit better let's acknowledge.

This issue of the MS Bulletin covers quite a few news items. We shall give an overview of the participation at the Ambilympix in Prague, the MS Seminar held at Hal-Ferh in October for MS patients and their carers, the Christmas re-union, a review of the Annual General Meeting and the accounts for the MS Society as presented during the AGM held on the 24 February 2001.

One important issue which cropped up at the AGM is the need for new volunteers to help with the work for the MS society. We must appreciate that all the work carried out at the society is purely voluntary and we need the support of any members or carers who can in some way or another dedicate some time, no matter how little one's contribution is. After all the MS Society is ours and we have to keep it going.



Is-Socjetà għandha żewġ pubblikazzjonijiet li huma ta' interess kbir għal kull min huwa milqut bl-MS. Dawn huma: *Xi Hadd li taf Għandu l-Multiple Sclerosis*. *Ktieb għat-tfal ta' pazjenti bl-MS*, adattat u maqlub għall-Malti minn Ms R. Grech, u *Multiple Sclerosis*, miktub min Dr S. Farrugia Randon. Għad fadal xi kopji ta' dawn il-pubblikazzjonijiet u min ikun interessat għandu jikkuntattja lis-Socjetà billi jikteb fl-indirizz *MS Society of Malta*, P.O. Box 209, CMR Marsa, jew inkella jagħmel kuntatt ma' xi hadd mill-membri tal-kumitat.

Kull korrisspondenza għandha tintbagħat f'dan l-indirizz:  
**Mutiple Sclerosis Society**  
P.O. Box 209  
C.M.R. Valletta

**Jekk għandkom xi artikli, esperjenzi, jew mistoqsijiet ta' natura medika, u tixtiequ li jiġu ppublikati fuq l-MS BULLETIN, intom mitlubin tindirizzawhom lill-Editur, Mr. Kenneth Muscat, fl-indirizz li jidher hawn fuq.**

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## Nicholson Award for 2000

Mr. Cor de Wilde-Verstey has been awarded the Year 2000 Nicholson Award for the International Caregiver of the Year.

Cor's wife Ann was diagnosed with MS thirty-three years ago and he has been looking after her all these years and taking care of their two boys. Since 1984 Ann's condition has deteriorated, and she is totally dependent and can hardly speak. Cor has had to quit his job in order to be by his wife's side.

His dedication has gone beyond nursing his wife. Cor is doing a lot of work in his home town in Holland organising meetings for persons with MS and their caretakers.

The Nicholson Award is named after Reid Nicholson one of the leading lights in the MS world who visited Malta at the invitation of our Society in 1999.

## Il-Multiple Sclerosis neghlbuha flimkien

minn Rose Grech

L-għarfien tal-marda Multiple Sclerosis illum il-ġurnata ntxtered sew f'pajjiżna. Il-Multiple Sclerosis (fil-qosor MS) hi marda kronika li taffettwa l-moħħ u s-sinsla tad-dahar. Il-moħħ hu bħal kompjuter li jibgħat il-messaġġi lill-ġisem biex jgħidlu x'għandu jagħmel. Is-sinsla tad-dahar hi bħal sett ta wajers hoxxnin bejn il-moħħ u n-nervituri tal-ġisem kollu.

Meta persuna jkollha l-Multiple Sclerosis dik il-qoxra (*myelin*) li tipproteġi n-nervituri tiġi affettwata b'tali mod li l-messaġġi ma jkunux jistgħu jgħaddu. Dan jikkawża ħafna sintomi li jvarjaw minn problemi fil-viżjoni, bħal ċpar fl-għajnejn, għal viżjoni doppja jew telf kompletament tal-vista għal perjodu ta' żmien. Sintomi oħra jinkludu nuqqas ta koordinazzjoni, sensazzjoni u għejja. F'ċerti kazi avvanzati jista' jkun hemm paralizi.

Din il-marda tvarja ħafna minn persuna għall-oħra. Fejn hi progressiva tista' tkun aggressiva tant li f'ċertu kazi wara xi attakk wieħed jista' jibqa jbatu b'xi diżabbiltà. F'kazi oħra l-individwu jirkupra kompletament jew jibqa' bi ftiit diżabbiltà.

Ħafna drabi huwa diffiċli li wieħed jagħmel dijanjozi tal-M.S. fi stadu bikri. Meta l-marda tidhol 'il ġewwa jkun aktar faċli permezz ta' testijiet, bħal 'Magnetic Resonance Imaging' (MRI).

Kull individwu jaġixxi b'mod differenti meta ssirlu dijanjozi tal-MS. Issib min qatt ma jkun sema' biha, waqt li oħrajn iħossu sens ta' serħan wara tant xhur u snin ta inċerterzza, jiġru mingħand tabib għall-ieħor. Xi wħud jistaqsu "Għaliex Jien?" u ħafna mistoqsijiet simili.

Dan kollu hu proċess mill-aktar komuni tant li hi normali li wieħed iħossa bi tqila biex jaċċetta din id-dijanjozi. Ħafna drabi l-pazjent jgħaddi minn perjodi ta' dwejjaq, rabja u biża'. Tant li kultant jirrifjuta li jammetti li saħansitra teżisti l-problema. Meta din l-imġieba tkompli tippersisti l-individwu jenħtieglu kura professjonali.

Il-proċess biex taċċetta l-marda mhux xi ħaġa daqshekk faċli. L-aktar meta l-persuna tkun f'età li tagħmel ħafna pjanijiet għall-futur. Taht dawn iċ-ċirkustanzi wieħed jinħtieg l-għajjnuna biex jikseb il-kontroll. Parir minn konsulent mediku jista' jgħin biex jiġu identifikati l-problemi u l-beżgħat biex b'hekk wieħed ikun jista' jegħlibhom. Pazjent ma jistax jifhalla jaqdef

waħdu. Minħabba li l-

MS hi marda li qatt ma tista' tbassar x'tista' ġġib magħha fil-futur jiġifieri f'liema stadju se tiżviluppa, dan ta' spiss johlq ħafna ansjetà. Persuna bi problemi fil-bużżeġa ta' l-awrina tista' tħossa aktar ansjuża dejjem tistenna xi katastrofu. Ħafna drabi l-ansjetà hi aktar ta' problema mill-marda fiha





nfisha tant li l-persuna tirrifujta li toħroġ mid-dar.

Minħabba li l-MS taffettwa s-sistema nervuża ċentrali, kwazi kull parti tal-ġisem tista' tiġi affettwata. Xi whud isibuha diffiċli li jikkellmu fuq aspetti sesswali. L-individwu jista' jhossu biered jew anki beżgħan minn kuntatti sesswali. Hafna minn dawn il-problemi jistgħu jiġu solvuti waqt diskussjoni ma' nies professjonali fejn wiehed jgħarbel l-aktar kura adatta għall-pazjent. It-tieni għajjnuna tiġi minn *support* li wiehed jirċievi minn persuni li jbatu b'din il-kundizzjoni. Meta persuna tipparteċipa fi gruppi jgħin biex taqşam il-problema ma' nies li għaddejjin minn esperjenzi simili.

Hafna li bbenefikaw mis-*support* li toffri s-Socjetà tal-'Multiple Sclerosis' ta' Malta għall-ewwel sabuha bi tqila li jattendu għal-laqgħat. Jista' jkun hemm minn min hu mgħobbi b'aktar diżabbiltà. Hawn irridu nifmhu li l-MS ma taffettwax lil kulhadd bl-istess mod. Jekk wiehed illum jara persuna bl-MS fuq sigġu tar-roti, ma jfissirx li se jigrilu l-istess. Hafna nies li ilhom ibatu minn din il-marda għal hafna snin jidhru normali bħal kull bniedem ieħor.

Issib min iħossu mbeżża', għalhekk jiddejjaq jisma' problemi u l-bezgħat ta' haddiehor meta huma għandhom biżżejjed. Hawn ta' min jifhem li fil-kumpanija ta' nies bħal dawn li wiehed jista' jsib l-għajjnuna u l-appoġġ li jinħtieg. Jgħin hafna li l-pazjenti bl-MS jaqsmu esperjenzi tagħhom ma' xulxin.

Jista' jkun li hemm raġuni oħra li tinkwieta lil hafna li jsibuha bi tqila jattendu għal-laqgħat li torganizza s-Socjetà tal-Multiple Sclerosis. Pajjiżna hu żgħir għalhekk in-nies magħrufa. Ma jhossuhomx komdi li juru li huma jbatu min din il-kundizzjoni, għalkemm l-MS la tinxtered u lanqas tittiehed. Għalhekk aktar ma tagħmilx sens. Fid-dinja hadd ma jgawdi l-privileġġ li ġismu jkun meħlus minn kull xorta ta' mard. Il-preżenza tiegħek biss hi biżżejjed biex tagħmel kuraġġ lil haddiehor.

Is-socjeta tal-'Multiple Sclerosis' toffri kull għajjnuna lil daww kollha milquta biex jaċċettaw din il-kundizzjoni. Li taċċetta l-MS ifisser li trid tidra tgħix b'din il-marda ta' hafna ucuħ. Fejn minkejja l-isfidi tremendi li tippreżenta l-MS wara l-proċess ta' aġġustament wiehed irid jifhem li l-hajja trid tibqa' sejra.

## News Update from America

- The Food and Drug Administration of the USA has approved use of the drug Novatrone (mitoxantrone for injection concentrate). This drug has been found useful for persons with secondary-progressive MS, with progressive-relapsing MS and with worsening relapsing-remitting MS.

- Investigators at the Mayo Clinic have reported success in promoting the re-growth of myelin in mice with MS-like disease by injecting them with immune-system proteins called 'monoclonal antibodies'. More research is going on about possible clinical trials in humans with MS.

- Large clinical trials are being carried out of an oral form of Copaxone, for persons with relapsing-relapsing MS. The trials which will last one year are meant to establish whether Copaxone can reduce the rate of MS relapses.

- Researchers at Cleveland Clinic and elsewhere showed that treatment with Avonex had beneficial effects on a number of cognitive functions on people with relapsing MS.

- A small study testing the ability of oral modafinil (Provigil) to fight fatigue, a common symptom of MS, shows promising results.



**Xellug u isfel:**  
*Il-membri li ħadu sehem fl-  
International Abilympics fi Praga.*

**Isfel xellug:**  
*Waqt il-Christmas Reception li  
saret fil-Milied fis-Suncrest Hotel.*





# THE M.S. SOCIETY OF MALTA

## Annual Report & Financial Statements for the year ended 31 December 2000

### *Income and expenditur statement*

	2000 Lm	1999 Lm	1998 Lm
<b>Income</b>			
Fund raising activities	792	801	1,343
Collection boxes	106	-	-
Membership fees	129	127	117
Donations			
- Physiotherapy	1,000	253	1,500
- Other	3,070	1,172	794
Government grant - NGO	-	-	300
Interest received	80	60	17
<b>Total Income</b>	<b>5,177</b>	<b>2,413</b>	<b>4,071</b>
<b>Expenditure</b>			
Administartion	363	330	283
Educational and awareness	775	1,598	1,177
Physiotherapy services	1,222	82	-
Collection boxes	688	-	-
<b>Total Expenditure</b>	<b>3,048</b>	<b>2,010</b>	<b>1,460</b>
<b>Surplus for the year</b>	<b>2,129</b>	<b>403</b>	<b>2,611</b>

### *Statement of accumulated surplus*

Accumulated surplus at 1 January	3,014	2,611	-
Surplus for the financial year	2,129	403	2,611
<b>Accumulated surplus at 31 December</b>	<b>5,143</b>	<b>3,014</b>	<b>2,611</b>
Appropriated as follows:			
<b>Physiotherapy fund</b>			
- Balance at 1 January	1,671	1,500	-
- Donations	1,000	253	1,500
	<b>2,671</b>	<b>1,753</b>	<b>1,500</b>
- Physiotherapy services	(1,222)	(82)	-
	<b>1,449</b>	<b>1,671</b>	<b>1,500</b>
- Balance at 31 December	3,694	1,343	1,111
<b>General fund</b>			
<b>Total accumulated funds at 31 December</b>	<b>5,143</b>	<b>3,014</b>	<b>2,611</b>