

Events ...

Visit of International MS Personality

MR. REID NICHOLSON



Our Society was honoured and delighted to host Mr. & Mrs. Reid Nicholson during the month of April. Mr. Nicholson who hails from Canada, is an international figure in the world of MS and sits on several MS National and international committees.

Mr. Nicholson came to Malta at the express invitation of our society, which is keen to strengthen its international contacts, especially through the International Federation of Multiple Sclerosis Societies (IFMSS).

During the few days he was in Malta, Mr. Nicholson had a gruelling programme of lectures, meetings and interviews all of which he undertook with tremendous enthusiasm, in spite of the great demands the programme made on his health.

Our members had the pleasure of listening to Mr. Nicholson at the talk he gave at the Hospice Movement on the Subject "The IFMSS and you". After the lecture, several members had the opportunity to talk to him individually. Two other public lectures he gave were aimed at members of voluntary organisations dealing with disability and the medical profession. Question and answer sessions at the lectures proved most interesting.

Mr. Nicholson accompanied members of the Society's Committee to meetings with the Minister of Social Policy and the Minister of Health. At both these meetings a number of important issues relating to possible improvement in services to persons with MS were raised.

Mr. Nicholson was interviewed by Miriam Dunn for the *Malta Independent* and appeared on television in the programme *The Breakfast Show*.

A young society like ours needs all the help and advice it can get and this was very generously given by Mr. & Mrs. Nicholson throughout their stay in Malta.

On behalf of all our members we should like to say a big THANK YOU to the Nicholsons. The work they have carried out in Malta will bear rich dividends in the years to come; already it has opened up new doors for our Society. Our thanks also to Mr. Godfrey Leone Ganado, our first Vice-President, who organised the visit in his usual professional manner. □

EDITORIAL ...

minn Kenneth Muscat

Yet again, we have the opportunity to meet each other via the Bulletin. We trust you are all well. The month of May is turning out to be a period when the society's members are organising themselves for a second awareness and fund-raising walk across the local sea-front.

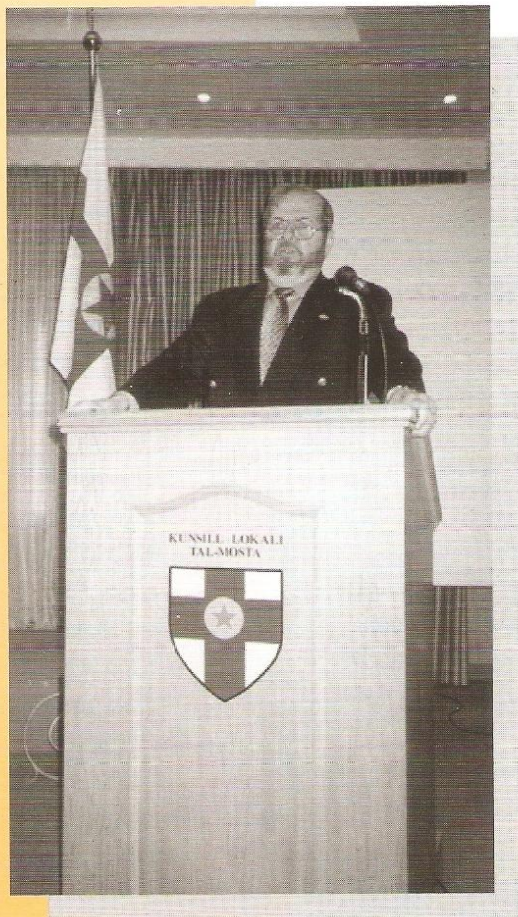
One point I would like to stress in this valuable space is that MS is not the end of the world. Many have readjusted their lives and are successfully getting on with them.

Although this is not an easy, exciting venture, YOU ARE NOT ALONE. The MS Society understands your feelings and how uncertain and uncomfortable you may be feeling. Our Society is there to give you the support and services you need. Our meetings provide you with the opportunity to talk to others and to share with them experiences of how you have coped and are still coping with the conditions of MS.

And we look forward to seeing you at the MS Walk on May 30!! Let's enjoy it.

Fuq ir-Radju

● Il-membri taghna
Rose Grech u Noel
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Prosit Rose u Noel.



*Reid Nicholson,
delivering one of his lectures
during his Malta visit.*

Words of encouragement

You and the IFMSS

Talk by Mr. Reid Nicholson to MS Society Members

6 April 1999 - Malta Hospice Movement, Balzan

Let me begin by taking you back over half a century, to the time when Bernard Lawry, a young man in New York City, was diagnosed with Multiple Sclerosis. In those days MS was said to be incurable. He obviously wasn't the first person to receive this diagnosis; that had happened many years earlier in France, but his case was and is very significant. You see, Bernard had a sister who couldn't accept the idea that MS was an incurable disease, and 54 years ago, Miss Sylvia Lawry chose to fight back. On May 1st 1945, Sylvia placed an advertisement in the *New York Times* that simply read: "Multiple Sclerosis. Will anyone recovered from it please communicate with patient. T272 Times".

Sylvia's eleven word ad set into motion a chain of events that has galvanised and mobilised people around the world. Her inquiry led to the formation of the National MS Society of the USA, then the MS Society of Canada and on to the International Federation of MS Societies in 1969. Her little ad in fact, has brought us all together this evening.

The issues I would like to address for you are: "Why an International Federation of Multiple Sclerosis Societies (IFMSS) and where does the individual fit in this IFMSS?" The answer to the first part of this question is almost self evident however. I think it may be worth repeating. To begin with, let me state a few basic but often ignored facts. First of all, we have no idea if the crucial breakthrough we seek, is going to come from St. Paul Malta or St. Paul Minnesota, or if it will come from Sydney Australia or Sydney Nova Scotia. Secondly, Multiple Sclerosis has no social, political or geographic limits, nor does it differentiate based on sex, religion or profession.

Once we understand the universal nature of MS, we cannot avoid the conclusion that the fight against it must also be universal. The IFMSS was formed to answer this need.

When I was diagnosed with MS in 1977, I went to a meeting of the local chapter of the Canadian MS Society. I was 37 years old and had no idea what my future held, or about the size, or shape of the organisation I was joining. Frankly, I'm not even sure why I joined. I had spent most of my early adult life in the Navy, and envisioned some type of pyramid structure. Of course, I

had no idea who was at the top, but I knew I was at the bottom. My idea of the organisation model of the MS World could not have been more wrong.

The MS Movement is not a pyramid at the local, national, or international level. In truth it has evolved into the most unique and fascinating organisation anyone could imagine. In the IFMSS model, each component part, shares a

common mission with the whole, and each component part is as critical as the whole in achieving that common mission. The IFMSS has been created by the members to further the mission, and only exists because the members require it to fulfil the mission. Furthermore the individual societies in turn only exist to achieve the mission. The mission, i.e., **"a world free of Multiple Sclerosis and its effects"**.

I like to think of the IFMSS organisation model as being more like an orange. The people are the little juice capsules, the societies are the segments, and holding it all together is the peel, which of course is the mission.

The IFMSS is a true partnership of 36 equal member MS Societies. Within the IFMSS every member Society has an equal voice. The federation represents several million people with MS and spans five continents.

The purpose of the IFMSS is to coordinate and further the work of national MS organisations throughout the world. This is done through a system of committees. It is governed by an executive, a board and a council.

Most important of all, the IFMSS has three stated priorities: **Integration, Stimulation** and **Information**. That is: the full integration of Persons with MS, the stimulation of scientific research into MS, and the distribution of educational and scientific information.

And so we all ask, "where do I fit in this world wide organisation". I've heard people ask that question since my earliest days in the MS Society. "What can I do, what difference can one person make?" I've heard it asked by persons with MS, by volunteers, and by staff. I've heard this question at local, national and international meetings.

The global MS Movement, the IFMSS and every member society is all about individuals. Remember Sylvia Lawry, the sister who refused to accept that MS was incurable. Remember her eleven word ad.

The history of the MS movement is a story of individuals, one individual in the beginning and now thousands of individuals, but all individuals. These individuals have only one thing in common: their commitment to our mission, eradicating Multiple Sclerosis and its effects.

Across the MS movement there has been the concern by individuals as to their role, and no doubt, there has been a spectrum of approaches as to the integration of all the individual talents and roles. First of all there have been those organisations that have tried a purely medical model. Their approach was to treat persons with MS as a recipient of services and excluded them from any meaningful role. This system denies the value of years of education and training, and divorces the organisation from those it is intended to serve.

Secondly, as you might expect, some organisations emerged that were 100% persons with MS. In these Societies, persons with MS controlled every decision, every act, at every level. The criteria to work, or to help was that you have MS, not that you have any level of competence.

In the first example we had a paternalistic organisation with little or no legitimacy, and in the second we had a popular based system without productivity. Fortunately within the MS movement, there are those who champion a third view, which I am happy to say has prevailed. It is our position at the IFMSS that an MS Society without persons with MS lacks credibility, while an MS Society comprised totally of persons with MS is nonproductive.

Each individual who comes to this fight, brings with them their own talents and experiences. Whether they are a person with MS or someone who has only heard the word, whether they are a college graduate or a school drop out, whether they are "a tinker, a tailor, a soldier or a sailor", we all have a role in this movement. □

We all have a role in the MS Society

On the Web

● For those of you who enjoy surfing the Internet, we would like to draw your attention to the website of the International Federation of MS Societies which may be accessed on:

ifmss.org.uk

This website provides all the latest information about developments in the management of MS and has received international recognition for its very high quality.

Barbecue

● Qed isiru thejjijiet għall-Barbecue għal nofs Lulju. Min hu f'pożizzjoni li jghin (daqq, żfin, kant, loghob, eċċ) għandu jċempel lil Joe Tabone fuq telefon 461325.

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News from the web ...

Reports on MS at top Neurology Meeting

The following latest news are reproduced from the IFMSS's website:

At the 51st Annual Meeting of the American Academy of Neurology in Toronto (April 17-24 1999), over 120 presentations were given on ongoing basic and clinical research related to MS from investigators around the world.

Among the highlights:

- An international clinical study has provided evidence that glatiramer acetate (Copaxone®) significantly reduces MS disease activity in the brain. A clinical study of 239 individuals with relapsing-remitting MS at 29 centres in Europe and Canada shows a statistically significant reduction in virtually all measures of MRI-detected brain lesion activity within 9 months of initiating treatment, as well as the expected reduction in relapse rate of 33%. These MRI data support the value of Copaxone for relapsing-remitting disease.
- Individuals with relapsing-remitting MS show progressive loss of brain volume and this may be slowed with interferon beta-1a (Avonex®) treatment. In individuals who had been treated with Avonex for two years, there was 55% less progression of atrophy. These data emphasize the importance of treatment with disease-modifying agents such as Avonex.
- The immunosuppressive drug mitoxantrone (Novantrone®) shows evidence of clinical and MRI-detected benefit in relapsing-remitting and secondary progressive MS. A multicenter European study examined the safety and efficacy of this agent, given by intravenous infusion once every three months for two years, in 188 individuals. There was a statistically slowing of progression and a reduction in relapse rates in drug-treated patients, and a reduction in new brain lesions.
- A small head-on comparison of efficacy between glatiramer acetate (Copaxone®) and interferon beta-1b (Betaseron®) indicates that the agents are equally effective in controlling MS exacerbations. In a study done in Israel, 58 individuals with relapsing MS received either Copaxone daily or every other day, or Betaseron every other day, all injected under the skin (subcutaneously), for two years. A significant reduction of relapse rate was seen in patients in all three groups, and all showed about the same slowing of progression of disability. This small study suggests that treatment with these agents has equivalent effects, but larger studies are required for confirmation. □

IT-TIENI MS WALK

Nhar il-Hadd 30 ta' Mejju niltaqgħu għat-tieni MS Walk mix-Chalet sa Balluta.

Din hija attività li għandha żewġ għanijiet prinċipali: l-ewwelnett li teduka lill-poplu dwar x'inhi l-MS għaliex hawn Malta f'it li xejn hu magħruf fuq din il-marda; it-tieni, li niġbru fondi għall-proġett tagħna biex nipprovdru servizz ta' fizjoterapija għall-persuni bl-MS.

Nittamaw li nsibu s-support meħtieġ minn kulhadd sabiex jerga' jkollna suċċess kbir bħas-sena li għaddiet.