

MagScene

Vision and MS

(Adapted from a publication of the MS Society of UK, MS Essentials for People Living with MS: Vision and MS, and written by Debbie Reeves, 2003)

For many people with MS, one of the early symptoms is a problem with vision. This may be in the form of temporary loss or blurring of vision, or double vision. Most people with MS who experience visual symptoms recover well. A small number of people may develop a persistent problem. This article discusses some of the basic facts about common vision problems in MS.

A problem with vision could be caused by a number of factors; it is important not to assume that all difficulties are due to MS. If you develop problems with your vision, speak to your GP or neurologist who may refer you to an optometrist or your neurologist for further diagnosis, consultation and advice.

Optic Neuritis?

Optic neuritis is a medical term to describe inflammation of the optic nerve. The optic nerve is the nerve of vision – the pathway that carries messages



from the eye to the brain. There is an association between optic neuritis and MS but not all people who have optic neuritis go on to develop MS.

Optic neuritis tends to come on over a few days. However, sometimes symptoms occur more quickly, either over a few hours or people wake up with their vision affected.

Optic neuritis tends to affect one eye but it can affect both eyes too, either at the same time or one after another. The effect on vision can also vary in optic neuritis. It can range from blurring of vision to someone

having 'no perception of light' (sight loss) in the affected eye or eyes. There may be a blurring or blankness in the centre of sight. Colour vision is also usually affected; colours are described as being darker or washed out.

Most people recover well from optic neuritis, usually with signs of improvement within three to five weeks and further improvements happening up to a year after symptoms first began. Following optic neuritis, vision tends to recover by itself. The early stages of recovery can be rapid, probably because it relates to



in this issue...

Wild China Cycle Challenge for MS	3	New Faces + Library Update	15
CEO's Corner	4	Lobbying the Government for Equipment + Disability Support	16
Celebrating MS Awareness Week	5	MSRA Roundtable + Emotional Expression	17
Complementary and Alternative Approaches: Part 2	6	Mr Wisdom's Brain Gain + MS Busibody	18
Update on Client Programs	8	Information & Education	19
Spotlight on MS	9	Behind the Scene	20
Planning Travel with MS: Part 1	13		

inflammation of the optic nerve subsiding. Occasionally, steroids are used to speed up the recovery of vision and may be given either as tablets or intravenously.

Eye Movement Problems

In MS, there can also be damage to the nerve pathways that control eye movement. For some people, this can lead to a lack of coordination between the two eyes. People with MS may experience problems when moving their eyes rapidly from side to side or when trying to follow the path of a moving object. Some people might experience involuntary eye movement.

Diplopia (double vision)

When the eyes do not move perfectly together, people may complain of diplopia or double vision – when two images appear from just one object. For some people, it can be the first symptom of MS. Others might experience diplopia after having MS for some time. Sometimes it can also be associated with nausea, vertigo and incoordination.

Diplopia usually recovers on its own over a few weeks, although recovery can take longer. As in optic neuritis, steroids may help to speed up recovery.

Nystagmus (involuntary eye movements)

Nystagmus refers to repetitive, to and fro, involuntary movement of the eyes. It can occur in a range of conditions, including MS. The eye movements can be marked or subtle, and can be from side to side, rotational or up and down.

In MS, people who have nystagmus are generally unaware that they have it. It is something doctors look for when testing eye movements. Occasionally, a person may experience 'oscillopsia' – a condition in which objects seem to move back and forth, to jerk, or to wiggle – which can in turn cause considerable difficulties in vision.

What is Low Vision?

Low vision refers to a vision loss that is severe enough to impede performance of vocational, recreational and/or social tasks, but still allows some visual discrimination. Low vision cannot be corrected to normal vision by regular eye-glasses, lenses or spectacles. The majority of people who are legally blind are included within the low vision classification.

Legally blind is a term used by government to define the conditions for which a person is

eligible for benefits and services provided for vision impaired people. A person who cannot see at six metres what a normally sighted person can see at 60 metres, or has a field of vision ten degrees or less in total (a normal field of vision is 180 degrees), is considered legally blind. Ninety-five percent of people who are legally blind people have some useful vision.

If your eye specialist tells you that you can be registered as legally blind, this does not necessarily mean you will lose all your sight – it means your eyesight has fallen below certain levels. Being registered may entitle you to a range of services, such as an assessment of your practical needs in the home and/or workplace and access to various gadgets, technology and assistive equipment.

Low Vision Services

Low vision services provide help for people with serious sight loss. Help comes in a variety of forms, with services varying depending on where you live. Low vision services may be located in hospital eye departments, in optometrists' practices and voluntary organisations for the visually impaired.

Optometrists are trained to assess, prescribe, fit and supply spectacles and lenses. They can also detect eye conditions and disorders.

Ophthalmic nurses are trained nurses who specialise in the care of eyes and minor treatment. They generally work in specialist eye hospitals and eye departments of local hospitals.

Ophthalmologists are doctors who specialise in treating eye disease. They are trained to diagnose eye conditions, undertake surgical operations and prescribe eye medication if required. An ophthalmologist can diagnose whether a vision problem is treatable. Diagnosis can also help determine how low vision services might best help.

Orthoptists are specially trained to make both eyes work together (binocular vision) and help with eye movements. They frequently work with children who have squints and other people who have double vision problems.

Rehabilitation health professionals, particularly occupational therapists, specialise in solving practical problems, such as getting about safely and carrying out daily activities. They can also provide a wide range of general information and advice.

Low Vision Clinics provide services to people who have been diagnosed with an eye condition for which there is no available treatment and who are seeking positive, helpful ways to adapt to their new situation.

Optometrists with specialised training in low vision services assess a person's vision and provide advice and aids that can help. Low vision services may include home visits, help in understanding vision loss, support for families, and assistance in accessing other services.

Royal Blind Society (RBS) is the major service provider in NSW and ACT for children and adults who are blind or vision impaired. Most RBS clients who receive rehabilitation services visit Vision Assist, where they receive services to help them make the most of their remaining sight in order to overcome the challenges at home and in the community. RBS also assists people who are blind or vision impaired to find paid employment, make a career change or retain a job that may be in jeopardy. It provides training to help people access printed information, produces information in accessible formats, and also offers advice on a broad range of equipment. Website: rbs.org.au and Information Line: 1300 134 560.

Vision Australia Foundation provides vital services and facilities for people who are blind or vision impaired. Services are designed to help people make the most of their remaining sight, to continue living independently, safely

and confidently in their own homes and include a national information and library service, RPHA (a network of community radio stations throughout Australia), which provides news information and entertainment for people unable to read standard print word), telephone information line, peer support, and access to technology and low vision clinics.

Website: www.visionaustralia.org.au and Information Line: 1800 331 000.

Guide Dogs NSW/ACT, as the name suggests, train dogs for people who are blind or vision impaired. In addition, they train people who are vision impaired to use canes and electronic aids to improve their mobility and independence, train companion dogs for children and adults who are disabled, and advocate on behalf of people they assist to make the community an easier place in which to live and work.

Website: www.guidedogs.com.au and phone: 02 9412 9300.

Independent Living Centre (ILC), based at Parramatta in Sydney, displays a comprehensive range of products and equipment to assist with day-to-day living. You can try out products and equipment and select those most suitable before you buy. The ILC can provide you with supplier details and approximate prices.

Website: ilcsw.asn.au and Information Line: 1300 885 886.

**Article prepared by Alex Hope,
Manager Knowledge Development**

Wild China Cycle Challenge for MS

Congratulations to the 39 MS fundraisers who recently completed the Wild China Cycle Challenge for MS. Each participant raised a minimum of \$5000 to be part of the challenge, and then rode 430km's through China's Yunnan Province.

A very inspiring effort was shown by three participants, who are living with MS and completed the journey.

If you would like to participate in a similar MS Challenge, or know of someone that might, please contact Luke Joyce at the MS Society on (02) 9413 4166 or visit www.msaustralia.org.au

Future cycling trips include Sri Lanka, Thailand/Laos, and Mongolia or Walk the Great Wall of China.



CEO's Corner

You would have read in the last CEO's Corner that we have been focusing on addressing the growing client demand being placed on MS Societies throughout Australia while at the same time facing flat or decreasing Government funding support and an increasingly competitive fundraising environment.

In an attempt to curb this increasingly difficult situation, the MS Societies of NSW and Victoria have embarked on Project Umbrella, an examination of the benefits to be gained from the operational integration of the two Societies.

This investigation is not just about avoiding duplication and therefore producing efficiencies between the two Societies. Its ultimate aim is to ensure that there is a vibrant and sustainable organisation supporting the delivery of expert and relevant services while working towards a cure for people with multiple sclerosis.

After endorsement by the MS Advisory Council (the peak advisory body made up of people with MS and carers drawn from all over NSW) in April, the Board of the MS Society of New South Wales reviewed the business case compiled by teams from across the two organisations and unanimously endorsed integration plans with the MS Society of Victoria, for the enhanced benefits it would ultimately deliver for people with MS.

The Board of MS Victoria reviewed the business case in May and also unanimously endorsed the integration plans with the MS Society of NSW.

Directors and senior management of Queensland, ACT, South Australian, and Tasmanian MS Societies have also been involved and kept up to speed with developments. They have also expressed their support of our plans.

These developments are however only the first step in the journey towards achieving our objective of maintaining and enhancing benefits for Australians living with MS.

I can say that in the time I have been with the Society this is the most important event ever contemplated and heralds a new era of service delivery and support for Australians with MS.

While there are still many detailed and technical issues to be worked through, the next major step

is a comprehensive communication plan to all stakeholders of the Society. Our intention is to meet with, and talk to, as many of our clients, members and other stakeholders as possible. We will be seeking your input and inviting you to put your questions and concerns to us. Details of meetings in your area will be made available as soon as possible.

With best regards,

Bill Northcote
Chief Executive Officer, MS Society of NSW



STOP PRESS

Dual CEOs to Lead Integrated Society

A historic joint meeting of the Boards of MS Victoria and MS New South Wales on 9 June 2005 unanimously appointed dual CEOs to lead the planned integration of the two MS Societies.

- Lindsay McMillan, currently CEO MS Victoria, will be CEO Mission, responsible for all integration activity related to client services, marketing and development, and corporate affairs for the integrated MS Society.
- Bill Northcote, currently CEO New South Wales, will be CEO Corporate, responsible for all integration activity related to finance, IT and communications, administration, property, quality management and the implementation of business operations for the integrated MS Society.

The People and Culture activity for the integrated MS Society will also report to Bill for administrative purposes, although it reports to both CEOs for strategic purposes.

Both CEOs have been also been charged with the responsibility for selecting and appointing people to fill the senior positions of General Manager (GM) Client Services, GM Marketing & Development, GM People and Culture, GM Shared Services and the heads of Corporate Affairs, Finance, Administration & Facilities, Procurement & Corporate Services.

Celebrating MS Awareness Week

On Sunday May 29, the MS Society celebrated the start of MS Awareness Week. To mark the occasion, a series of events were organised to raise awareness, funds and hope for people with MS.

The Society, people with MS and supporters kicked up their heels for events such as the ninth Sailing Regatta hosted by the Royal Sydney Yacht Squadron on Sydney Harbour, the start of the MS Readathon™ program, as well as the MS Harbourside Walk & Fun Run, which celebrated its fifteenth anniversary this year.

A new theme ran through the 2005 MS Awareness Week campaign, entitled, "What you didn't know about MS."

The theme explored the following questions:

Did you know that 20% of people with multiple sclerosis use a wheelchair?

The average age of diagnosis is 32?

Three times more women than men have MS?

No? You do now.

The idea behind this particular awareness campaign was to educate the community about multiple sclerosis and dispel common myths about the disease, all to build wider support for people with MS.

The awareness promotion took the shape of a small convenience advertising campaign in the restrooms of selected shopping centres in NSW. From May 5 – June 5, a total of 116 advertisements were displayed in shopping venues, which targeted both men and women between the ages of 20 and 40. The distribution of this program ensured the placement of messages in centres situated in both metropolitan and regional NSW. The advertisements appeared in a total of 12 venues, which reached approximately 2.9 million patrons per week for four weeks. The promotion of the key messages of MS Awareness Week aimed to create greater awareness in the community about multiple sclerosis.

Multiple Sclerosis Awareness Week May 29 - June 4, 2005

WHAT YOU DIDN'T KNOW ABOUT MS

Did you know that less than 20% of people with multiple sclerosis use a wheelchair?

The average age of diagnosis is 32?

Three times as many women as men have MS?

**NO?
YOU DO NOW.**

1800 CURE MS

This year, MS Awareness Week May 29 - June 4 is educating the community about multiple sclerosis and dispelling common myths about the disease, all to build wider support for people with MS.

The MS Society helps people with MS to live well.

Convenience Advertising
1800 4000 0000

MS AUSTRALIA
1800 4000 0000

In addition to the convenience advertising, the MS Society recruited the support of the city of Sydney to help promote MS awareness in the big smoke. The city of Sydney banner program allowed the Society to profile the MS logo throughout the main thoroughfares of Sydney including Martin Place, George Street and Circular Quay. Over 130 banners were raised for two weeks on May 29, which awarded MS a strong presence alongside prominent Sydney landmarks, seen daily by over 600,000 residents, workers and visitors.

Finally, the MS Society encouraged support from metropolitan and regional media outlets to promote awareness. Listeners and readers of radio and news were motivated to support people with MS by donating or joining in a local event. MS Publicity would like to thank those people who volunteered their time to assist the 2005 Awareness Week campaign by participating in a number of interviews with media contacts of the Society.

Complementary and Alternative Approaches: Part 2

This article forms the second part of a short series on complementary approaches, which began in the March issue of MagScene with a general overview of the use of traditional, complementary and alternative medicine. Part 2 provides background information on the use of complementary and alternative medicine in the general population and in people with MS. The use of herbal medicines is also addressed.

Use of Complementary and Alternative Medicine (CAM)

There have been a variety of studies investigating the use of CAM in the general population. A US study conducted in 1997 and reported in 1998 found that 42% of the general population used some form of CAM, with an annual expenditure for CAM professional services of \$US 21 billion. This study also found that CAM use was relatively high in people with chronic conditions, women and people between the ages of 35 and 49.

Studies of CAM use in people with MS are more limited. A recent US survey found that nearly 60% of people with MS had used CAM and that, on average, individuals used two or three different forms of CAM. A preliminary report of a Canadian study indicated that 67% of people with MS used CAM. It is also notable that the majority of people with MS and the general population use CAM in combination with conventional medicine.

Types of CAM

You will recall from Part 1 that CAM refers to a broad set of health-care practices that are not integrated into the dominant health care system (WHO, 2004). More specifically, CAM therapies may be categorised into six broad groups: biologically-based therapies; alternative medical systems; lifestyle and disease prevention; mind-body medicine; manipulative and body-based systems; biofield medicine and bioelectromagnetics:

Biologically-based therapies are those that generally include herbs, supplements and diet. There are other biologically-based therapies you may have heard about such as cooling therapy for MS.



Alternative medical systems include homeopathy, acupuncture and traditional Chinese medicine.

Lifestyle and disease prevention usually refers to the use of healthy lifestyle behaviours such as exercise.

Mind-body medicine refers to those therapies that attempt to use the power of the mind to alter body processes, including biofeedback, meditation, prayer and spirituality.

Manipulative and body-based systems include practices such as chiropractic and massage therapy.

Biofield medicine refers broadly to therapies that assume that there is an energy field within the body and includes practices such as acupuncture, traditional Chinese medicine and therapeutic touch.

Bioelectromagnetics is the use of magnets and magnetic fields.

Herbal Medicine

Herbal medicine is the most popularly used form of CAM medication therapy (WHO, 2004). Its popularity may be partly due to the fact that it is very accessible through pharmacies, supermarkets and specialist health food stores. In addition, there are an increasing number of professional herbalists treating people with a variety of conditions, ailments and complaints. Herbal medicines include herbs, herbal materials, herbal preparations and finished herbal products:

Herbs include crude plant material such as leaves, flowers, fruit, seeds, stems, wood, bark, roots or other plant parts, which may be entire, fragmented or powdered.

Herbal materials include herbs, fresh juices, fixed oils, essential oils, resins and dry powders of herbs. These materials may be processed by steaming, roasting, or stir-baking with honey, alcoholic beverages or other materials.

Herbal preparations are the basis for finished herbal products and may include powdered herbal materials, or extracts, tinctures and fatty oils of herbal materials. They are produced by extraction, purification, concentration, or other physical or biological processes. They also include preparations made by steeping or heating herbal materials in alcoholic beverages, honey, or in other materials.

Finished herbal products or mixture products consist of herbal preparations made from one or more herbs and may contain excipients (inert substances, which are added to drugs to provide bulk – for example in tablets) in addition to the active ingredients. However, finished products or mixture products to which chemically defined active substances have been added, including synthetic compounds, are not considered to be herbal.

Although the use of herbal medicine has grown extensively over the past decade, several misconceptions about herbs remain. One popular misconception is that herbs are “natural” and are not really drugs. Although naturally occurring, herbs contain many different chemicals, some of which have not yet been identified or characterised. These chemicals may also produce an adverse effect, and may interact with prescription



medications and/or the MS disease process. Some plants can be quite toxic at certain levels and some, such as certain types of fungi, can in fact be poisonous. Another concern is the lack of regulations to ensure the composition, quality, safety and efficacy of herbal preparations.

In considering the use of herbs, it is generally recommended that they only be used for a short time and for benign, self-limiting conditions. Herbs should be avoided by women who are pregnant or breast-feeding; people with multiple medical problems; and people who take multiple medications. In summary, herbs should be used with caution and in consultation with a general practitioner.

Bibliography:

Bowling, A.C., Ibrahim, R. & Stewart, T.M. Alternative Medicine and Multiple Sclerosis: An Objective Review From an American Perspective. International Journal of MS Care, 2000; 2(3): 3 - end.
http://www.ms-care.org/journal/a0009/page_03.cfm

WHO Guidelines on Developing Consumer Information on Proper Use of Traditional, Complementary and Alternative Medicine. Switzerland: World Health Organisation, 2004.

Examples of CAM therapies that have been suggested in the management of multiple sclerosis will be reviewed in the September issue of MagScene.

Update on Client Programs



One of the key areas raised by readers who responded to the client satisfaction survey in 2004 was that people with MS and their families are not always familiar with all the client programs offered by the MS Society.

My last column highlighted some of our programs, including **MS Connect™ 1800 042 138**, our telephone and email information and support service; our state wide **Outreach Program**; and the upcoming launch of our new look **Recreation Program**. The focus of my article this issue is to give you an overview of some of the other programs we currently provide. We currently provide, in collaboration with local health and community services.

The MS Society has a **Library and Information Service** located at the Studdy MS Centre at Lidcombe in Sydney. This specialist library holds a range of books, videos, and current readings on MS, which are available for loan. The library also supports MS Connect with the searching and monitoring of up-to-date international literature on MS, MS management and research, and makes this available via the Society's website, the Society's Intranet, interlibrary loans, and the development of information articles and reference material.

The **Newly Diagnosed Program** provides access to written materials, support options and tailored information sessions and teleconferences for people newly diagnosed and their families. **Knowledge is Power** is a national at-home educational series for people recently diagnosed and can be received by post or by email. The 10-week series provides up to date facts about many aspects of MS.

Our state wide **MS & Beyond** education program covers a range of topics on symptom and lifestyle management, which are delivered through face-to-face sessions, workshops and forums and by telephone link up. The Society has recently appointed a new **Family Education Program** Coordinator, who will be responsible for further developing our information and education resources for families and caregivers. We are also exploring new ways to bring information and education to you via videoconferencing and the Internet in the future.

The **Immunotherapy Support Program**, and its team of specialist nurses, provides information on MS medications, training and education in injection techniques, advice and support in the management of side effects, and education for community nurses.

The MS Society also supports a **MS Clinic** located at the Brain and Mind Institute in Sydney, which offers neurology consultation by appointment. A visiting Urologist also provides a fortnightly **Urology Clinic** at the Studdy MS Centre, for consultation on MS specific bladder, bowel and sexuality issues. The **Continence Advisory Service** offers information, screening, specialist advice and referral to community continence advisors, and assessment and management strategies through multi-disciplinary team assessments and rural consultation visits.

The MS Society offers health and lifestyle assessment and consultation by our team of health professionals who specialise in MS. We work with the person with MS in planning best ways to manage the challenges of MS in a way that complements existing health and medical services. Our team of skilled health professionals includes physiotherapists, occupational therapists, nurses, clinical psychologists, neuropsychologists, and outreach workers. Assessments are mostly conducted at our Lidcombe head office and during rural consultation visits. **Lifestyle Programs** include fitness and mobility programs, fatigue and memory management programs, individual and group sessions on managing depression, and employment support, to name a few.

To find out more about MS Society programs and services, please contact **MS Connect™ 1800 042 138**, Monday to Friday 9am – 4.30pm.

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Research Highlights and Clinical Updates

This issue of Spotlight is a compilation of recent research highlights, including birth month and risk of MS, response to beta interferon treatment, and exposure to infant siblings and risk of MS.

Most of these excerpts have been reproduced with permission from the MS Society of UK and US National MS Society Research Bulletins and Clinical updates. These Research Bulletins and Clinical Updates often contain summaries from journals and other sources of information that are independent of and do not necessarily represent the views of the MS Societies. Readers should always speak to their neurologist or GP for specific information and advice (Ed).

Birth Month and Risk of MS: Review

Title: Timing of birth and risk of multiple sclerosis: population based study.

Authors: C Willer, D Dymont, A Sadovnick, P Rothwell, T Murray & G Ebers for the Canadian Collaborative Study Group.

Place of Report: Vancouver, Canada.

Journal Reference: British Medical Journal, 2005. Vol. 330, pages 120-123.

Research Summary

It is widely accepted that a combination of genetic and environmental factors act to increase a person's susceptibility to developing MS. A number of environmental factors have been suggested, including viruses and climate. This study looked at the effect of month of birth on the risk of developing MS, in northern hemisphere countries. The researchers investigated birth month for 17,874 people with MS in Canada. This was compared to two different groups for comparison – people born in Canada without MS and unaffected siblings of those people with MS. Data on birth

month was also collected from 8702 people with MS in England and 2356 people in Scotland.

Birth months for these individuals were compared against randomly selected records. Results from the Canadian data showed significantly fewer people with MS were born in November, compared with either comparison group. Significantly fewer people with MS in England were born in November (10% of the sample) compared to significantly more (16.3%), born in May. After combining results from other large collections of data on birth months, the authors calculated that the results represent a 19% lower risk of developing MS for those born in November, compared to those born in May. This birth month effect was highest in Scotland, where MS prevalence is highest.

One of the striking features of MS is its greater prevalence in countries further from the equator. Previous research has linked sun exposure (UV radiation) to MS risk, suggesting this may account for the distinctive geographical distribution of MS. However, studies so far have not been conclusive. The authors of this study suggest that environmental effects, such as UV radiation acting on the mother during pregnancy may influence the development of the nervous or immune systems or both. This could potentially affect an individual's risk of developing MS in later life, although further research is needed to clarify this effect.



Key Messages

- Both genetic and environmental factors act to increase a person's susceptibility to developing MS.
- This study looked at the effect of month of birth on the risk of developing MS, in northern hemisphere countries.
- The birth months of people in Canada, England and Scotland were compared to people without MS.
- Results showed that significantly fewer people with MS were born in November, compared to significantly more in May.
- The authors calculated those born in November had a 19% lower risk of developing MS, compared to those born in May.
- The authors suggest that environmental effects, such as UV radiation acting on the mother during pregnancy may influence the development of the nervous or immune systems or both.
- Further research is needed to clarify this effect.

A spokesman for the UK MS Society, said, "This is an interesting study which adds weight to the accepted view that something related to the environment – including around the time of birth - may influence the development of MS. It is also worth noting it does not negate the likelihood of environmental factors operating at other times as well. It is another piece in a very complex jigsaw of research."

Source:

http://www.mssociety.org.uk/doc_store/Research_Bulletin_42.pdf

Predicting Response to Beta Interferon Treatment: Review

Title: Biological responsiveness to first injections of interferon-beta in patients with multiple sclerosis.

Authors: F Gilli, F Marnetto, M Caldano, A Sala, S Malucchi, A Di Sapio, Mcapobianco & A Bertolotto.

Place of Report: Torino, Italy.

Journal Reference: Journal of Neuroimmunology, 2005. Vol. 158, pages 195-203.

Research Summary

Beta interferon is currently the main treatment for relapsing forms of MS. This therapy has been shown, on average, to reduce relapse rate by around a third. However, not everyone has a favourable response to treatment, although this is often not possible to determine until months (or years) of therapy use. Previous research has shown that beta interferon causes increased production of a protein known as myxovirus resistance protein A (MxA). Over time, some people develop "neutralising antibodies" (NABs) to beta interferon, which reduce the effectiveness of the drugs. When this occurs, people no longer produce MxA in response to beta interferon.

This study investigated whether MxA was produced after a first injection of beta interferon, in order to investigate the possibility of using MxA as a marker of drug effectiveness. Levels of MxA production were measured in 96 people with MS who were receiving their first dose of beta interferon. 24 volunteers without MS also received beta interferon as a comparison. Blood samples were collected from all participants immediately before the first injection and then three and 24 hours after the first injection and 12 hours after the second injection.

Results showed that low levels of MxA were evident in all the participants in both groups before injection of beta interferon (as expected). An increase in production was evident three hours after injection in all participants, with levels reaching a peak 12 hours after injection. Levels did, however vary between participants. There were no significant differences between the levels of MxA detected with different beta interferon products.

These results indicate that beta interferon has a "biological effect", and that the reductions in effectiveness experienced by some people develop over the course of treatment, rather than people failing to respond initially. The results of this report suggest that measuring MxA production during the course of beta interferon therapy may help in determining whether people are responding beneficially to therapy.

Key Messages

- Beta interferon is the main treatment for relapsing forms of MS, reducing relapse rates, on average by around a third.
- Some people do not respond to treatment, although this is often not evident for months or years.
- MxA is a protein produced in response to beta interferon and measured in this study as a way of evaluating beta interferon effectiveness.
- Levels of MxA were measured in people with and without MS, after a first injection of beta interferon.
- MxA was produced in response to beta interferon in all participants.
- These results indicate that beta interferon has a "biological effect" initially – any reductions in effectiveness appear to build up over time, rather than be present initially.
- Measuring levels of MxA production during beta interferon therapy may help determining ongoing therapy effectiveness.

Source:

http://www.mssociety.org.uk/doc_store/Research_Bulletin_42.pdf

Identifying People Who Don't Respond to Treatment: Review

Title: Identifying and treating patients with suboptimal responses.

Authors: B Cohen, O Khan, D Jeffrey et al.

Place of Report: USA.

Journal Reference: Neurology, 2005. Vol. 63, Supplement 6, pages s33-s40.

Research Summary

MS, particularly in the early stages, is characterised by inflammation, in which cells from the immune system enter the central nervous system (CNS - brain and spinal cord) and attack nerve fibres and their protective myelin sheath. Higher levels of inflammation are linked to the occurrence of relapses. Relapses, in turn, have been linked to nerve fibre loss, which can result in permanent disability. Therefore, the reduction of inflammation early in the disease may be important in reducing subsequent disability.

The disease-modifying drugs currently used in MS, such as beta interferon and Copaxone are aimed at reducing this inflammation. Consequently, it is important to identify people who are not responding to disease modifying treatment in order to enable consideration of other treatment options before nerve fibre loss occurs. Currently, there are no validated criteria to identify a "non-responder" to treatment. This report is the collective opinion of a number of neurologists from around the US, brought together to develop a consensus for defining a "non-responder" to the disease-modifying drugs.

Measuring levels of inflammation is one method of determining treatment effectiveness. Levels of inflammation can be assessed using MRI, a noninvasive technique used to visualise areas of damage in the CNS. The report concluded that all people with MS should receive a "baseline" MRI scan to assess levels of inflammation before starting disease-modifying treatment.

It was agreed that it takes 6-12 months to judge the effects of disease-modifying treatments, and that after this time, clinical assessment (e.g. medical history, physical examination) could identify non-responders as those people who:

- Experience more than one relapse a year
- Experience an increased relapse rate, compared to before treatment
- Experience relapses, which affect multiple parts of their body
- Do not recover from relapses or experience progressive impairment

Mitoxantrone (a potent immune system suppressant used in the treatment of some forms of cancer) was identified as a potential alternative therapy for people with MS identified as non-responders. It was agreed that use of this is most likely to be beneficial for people with MS affected by:

- Accumulating disability as a result of relapses
- Rapid disability progression
- Ongoing inflammation, as determined by MRI



Treatment with mitoxantrone is thought to be most effective earlier in the course of MS, when inflammation is greatest. This report highlights that MRI and clinical assessment are useful in determining people with MS who don't respond to disease-modifying treatment. Once non-responders have been identified, changing to a combination of therapies or a different disease-modifying agent such as mitoxantrone are options, although more information is needed to evaluate the potential value of alternative treatments and dosing patterns.

Key Messages

- In MS a number of events occur including inflammation, damage to myelin and nerve fibre loss.
- Inflammation is linked to relapses, which in turn is linked to nerve fibre loss and permanent disability.
- Current disease-modifying therapies reduce inflammation but not everyone responds to treatment.
- People experiencing more than one relapse a year, an increased relapse rate or poor recovery could be assessed as "nonresponders".
- Mitoxantrone is a possible alternative treatment that may be beneficial where there is rapid disability progression.

- MRI and clinical assessment are useful in determining people with MS who don't respond to disease-modifying treatment.
- More information is needed to evaluate the potential value of alternative treatments and dosing patterns.

Source:

http://www.msociety.org.uk/doc_store/Research_Bulletin_43.pdf

Exposure to Infant Siblings and MS Risk

Australian researchers, Anne-Louise Ponsonby and colleagues, report that exposure to a younger sibling's infections during the first six years of life helps the elder child's immune system develop and cut the risk of multiple sclerosis (MS) later on. The authors suggest that this study may strengthen the "hygiene hypothesis" - that infections early in life may alter immune activity and reduce the risk of developing allergies and auto-immune diseases such as MS in adulthood.

The researchers looked at the life histories of 136 Tasmanian adults with multiple sclerosis and compared them with 272 without the disease. The results suggest that the longer people in the first six years of life were cumulatively exposed to any siblings younger than two years, the more reduced their risk of developing MS.

Longer exposure to a younger brother or sister also translated into a lower risk of developing mononucleosis (commonly referred to as glandular fever) and lessened the chances of an exaggerated immune response to the Epstein-Barr virus. The researchers also investigated past sun exposure and found that the association between having younger siblings by age six years and reduced risk of MS was significantly stronger in people who had higher winter sun exposure during childhood.

Further research is needed to confirm the findings published earlier this year in the *Journal of the American Medical Association* (JAMA 2005; 293:463-469).

Those readers who have access to the Internet might be interested in downloading the Research Bulletins available on the Multiple Sclerosis International Federation website, www.msif.org, or by following this link: http://www.msif.org/en/research/research_bulletins/index.html

Planning Travel with MS: Part 1



This is the first in a four-part series of travel advice articles by Bruce Mumford. Bruce is an example to all those who use a wheelchair for mobility and feel that they should take the family on that holiday they always dreamed of but did not think was possible (Ed).

Having returned from around two and a half months overseas with the family, I have quite a few tips I'd like to pass on to readers.

Before going, I wrote to MagScene requesting travel advice. I received a number of helpful emails and phone calls back. Hopefully my ideas here will be of practical use to others.

I've had MS for around 15 years and have gradually 'progressed' from a limp, to a walking stick, to Canadian crutches, to a walking frame and now (for travelling) to an electric wheelchair. I used to be a drama teacher, but had to retire 8 years ago when it became obvious I wasn't going to be able to get the support I needed from the Department of Education to stay on.

My wife Louise suggested going overseas nearly 2 years ago - while we could still take the family (two boys: Ashley 14 and Rohan 10) and while they still wanted to go with us!

My first reaction was that we just wouldn't be able to do it. Then I thought about it and realised this trip wasn't just for me. The boys would remember it for the rest of their lives - and at least the family wanted to go with me.



So we decided to take the plunge: a week in London and then 3 weeks touring the UK; a week in Normandy and then another in the Loire Valley; Paris for Xmas before staying with Belgian friends near Antwerp. While with them we did a tour of Bavaria, Prague and Trier, before returning to Paris and then home with a stopover in Tokyo.

My assessment: certainly not easier than we expected - but definitely worth it!

Before Going

Everyone needs to prepare for a trip, but when you have MS, you need to do a lot more. There's injections to order - you can get a special permit to order several months supply of Betaferon for instance to take with you. Never try to buy it overseas. It will be enormously expensive, or may not be available.

Unfortunately, those days of just dropping into a town and grabbing somewhere to stay on the spur of the moment are over. Most places in Europe are upstairs and many don't have lifts. Often you'll find that the bedroom is downstairs and the bathroom is upstairs, or vice versa. So you just have to book ahead - the Internet is a wonderful (and cheap) way of doing so.

You also need to choose a good airline and inform them of your special needs. We went with JAL and they were great. Most airlines will take your wheelchair for free.

Get several copies of letters from your doctor and neurologist explaining your need for needles and all those pills you'll be taking. And there are lots. We virtually needed one case just for all my paraphernalia.

You'll want travel insurance - if only to cover any medical emergencies. We had to pay a little

more to cover my "pre-existing condition", but it wasn't at all hard to get.

I bought a lightweight partially collapsible electric wheelchair especially for the trip. Luckily I bought it early enough ahead to iron out a few teething problems and to get used to using it (at the expense of our house, which has been gradually destroyed by my earlier miscalculations). My wife began cursing the wheelchair early in our trip as its rather small battery began running out of charge and I had to keep finding power points and wait for a re-charge. Some places were reluctant to let you use their power, so I found it better not to ask, but to simply whip out my battery charger and plug in. Edinburgh castle for instance, refused to let me use their power points as it was "still an operating military base". I suppose I could have been a terrorist. I certainly felt like one!

The Louvre had covers over all their power points, which would not permit my adaptor to plug in. They had manual wheelchairs available, but you had to show your passport to get one. So while my wife walked back to our apartment for my passport I waited with my chair, re-charging it at a power point whose cover had been mysteriously snapped off. . .

Take plenty of power adaptors too as you'll certainly lose some. You also have to get used to a lot of sitting around waiting for your chair to re-charge. But that's OK. With MS you get used to sitting around a bit. And for us it's usually a lot safer.

To be fair, my chair really wasn't made to go halfway across London (which I tried unsuccessfully to do). What I discovered in York was that it was a much better idea to hire an electric scooter for the day – they have bigger wheels and bigger batteries. Unfortunately no other city after York (including Edinburgh, Paris and Prague) had a 'shopmobility' place where I could hire one. But it's certainly worth checking out with the local tourist office.

The electric chair gave me a level of independence. I could look at what I wanted and go where I wanted; and often get lost without wanting to. In crowds, a flag would have been a good idea, as you're quite a bit lower than most pedestrians. In Belgium we got a lend of a manual wheelchair and Louise and Ashley got lots of exercise pushing me around cobbled streets and up and down

gutters. At least they knew where I was, but I felt a bit less mobile and a bit like the guy in 'Little Britain' (although without his ability to occasionally jump out of the chair!)

And don't forget your disabled parking pass, if you've got one. Even though the UK and many other countries don't actually accept overseas disabled parking permits, it's unlikely a parking officer will make trouble over it. In fact, in all our time overseas we never once had any trouble using it. The only time we did have trouble was in Prague where my Belgian friend had his wheels clamped by the Czech Police for parking in a disabled spot. The concierge at the hotel explained that the police "can't read English and aren't very smart anyway", so my friend simply took a picture of an international disabled symbol and had it enlarged, laminated and put it on the car. After that we had no problems. Lesson; take a few Disabled symbols with you as well!

Bruce Mumford, Burrawang

Sights to See in New South Wales

This is a big wide wonderful world and we in Australia live in one of the most select places for those who want to travel. People with MS are not excluded and costs need not be high.

Recently we went on a brief trip to Bathurst – only a couple of hours from Sydney, along the Great Western Highway and via the spectacular Blue Mountains. During Spring and Autumn, the floral colours and trees will always impress.

If your interest is Australian History, Bathurst presents a fine opportunity to continue your studies. Sight seeing in Bathurst is made easy by the Visitor Information Centre, on your left as you drive into town. Here you can collect your Rotary Heritage Drive Map for a guide to 38 points of interest around the town. The map details each of the items you will see in a drive of 60 to 90 minutes.

Bathurst is only one of a number of beautiful towns in New South Wales. The aim of this note is to remind those who want to travel that there is a great deal that can be done without necessarily needing to spend a lot or cover long distances.

Peter, Leura

Library Update

The library responds to a large number of requests for information on complementary medicine. These enquiries may be about a particular resource that has recently been in the news or suggested by a friend or staff member or about a specific treatment.

If a requested resource from the Library collection does not contain current evidence-based information then the item will have a "sticker" on the front cover informing you of that fact. These resources are often personal stories containing inspiring and positive attitudes, which make the reader also feel hopeful and more positive about managing MS.

The Library also holds a number of authoritative resources, which can be used to find out about specific or general treatments. Some of these are listed below and all the resources mentioned here can be borrowed from the library by emailing library@msnsw.org.au or phoning 02 9646 0600.

Thomas, Richard. *The natural way: multiple sclerosis* -- Great Britain: Element Books Ltd, 1995.

Roberts, Gill Symonds, Sarah (cover) Burnett Pubs London (producer/designer). *Complementary therapies: managing MS symptoms through alternative treatments* -- London: MSS Great Britain and Northern Ireland, 1997.

Bowling, A. *Alternative medicine and multiple sclerosis* -- New York: Demos Medical Publishing Inc, 2000; copyright states 2001.

Graham, Judy. *The Multiple Sclerosis Resource Centre: A to Z guide to complementary Therapies* -- Essex: Multiple Sclerosis Resource Centre, 2000.

Peters, D (ed). *Understanding the placebo effect in complementary medicine. Theory, practice and research.* -- Edinburgh: Churchill Livingstone, 2001.

Polman, C et al. *Multiple sclerosis: the guide to treatment and management* -- 5th ed. -- New York: Demos Medical Publishing Inc, 2001.

Hay, Louise. *You can heal your life* -- Concord, NSW: Specialist Publications, 1988.

Fetrow, C Avila, J. *Professional's handbook of complementary and alternative medicines* -- USA: Springhouse Corp, 1999.

New Faces at the Society

Rachael Wright joined the MS Society's Lifestyle Management Team in January this year and is based at the Studdy MS Centre.

She is employed as a full-time occupational therapist and will also join the MS Connect Team in June. Rachael is looking forward to providing assessment and consultation on a range of symptom and lifestyle issues. She will also have an educative role for people with MS and health professionals and will be working closely with occupational therapists across New South Wales.



Belinda Bungate is our new receptionist and the friendly voice you will hear at the end of the phone when you contact the Studdy MS Centre at Lidcombe.

She started at the MS Society in April and will be kept busy answering and directing incoming calls, greeting visitors to the centre, and helping with a whole range of administrative tasks that help keep our head office going. Belinda previously worked as practice manager at a physiotherapy practice.



Luke Edwards is the new fundraising coordinator for the Outdoor Events team.

In his words, "I am here to look after and motivate existing fundraisers and source new ways to fundraise through our events." Luke's colourful and diverse background includes recruitment, information technology, finance, tour operator and an unusual stint as co-host of the 2004 World Sauna Championships! He is looking forward to meeting you at future events.



Lobbying the Government for Equipment

The MS Society is working closely with the Physical Disability Council of NSW in lobbying State Government to significantly enhance their investment in the NSW Program of Appliances for Disabled People (PADP).

A coalition of over 60 health and disability organisations representing people with equipment needs, calls on the Government for an immediate injection of \$14 million into PADP to relieve current unmet need for essential equipment and an enhancement of funding to PADP to \$36.4 million per annum to meet future need for essential equipment.

This amount would still be 0.4% or less than half of 1% of the total Government allocation to the Health Budget and investing funds in PADP will lead to reductions in expenditure

elsewhere in health and specialist disability services.

How Can You Help?

If you are waiting for equipment through the PADP scheme, how about volunteering your story to be part of a fax campaign to the Premier, the Treasurer and the Health Minister (all your personal details will be removed)?

Or you might like to be part of the Parliamentary presence campaign, whereby representatives who use PADP are present during question time 2-3pm on Tuesdays when Parliament is sitting.

If you would like to help in either of these ways, please contact Bronwyn Moore at the Physical Disability Council of NSW on 02 9552 1606.

Disability Support Pension

People with MS and Workforce Participation

Following the announcement of the proposed changes to the Disability Support Pension (DSP) and the Federal Government's intention to encourage people with disabilities into the workforce, MS Australia (MSA) conducted a national consultation with people with MS.

A response has been drawn from this consultation, the Australian MS Longitudinal Study (AMSLS) and other papers previously prepared by MSA, and forwarded to the Minister for Employment and Workplace Relations.

MS Australia has a vital interest in this area of inquiry as employment and financial security are major life issues for people with MS and their families. The AMSLS recently released a report on the Economic Impact of MS in Australia, where it has been demonstrated that the participation rate in employment of people with MS is significantly lower than the general Australian population.

The MSA response challenges Government to consider:

- The realities of the unpredictability and progressive nature of MS and its financial impact on people with MS and their families
- Workforce participation reforms that enable people to stay at work as long as possible
- Continuing to support people working part-time with part DSP
- Ways to encourage more supportive and flexible workplaces
- Targeted labour market programs that focus on people with chronic illnesses
- Providing adequate income and health supports for those that can no longer work.

A full copy of the detailed response can be found on the MS Australia website www.msaustralia.org.au

Brendon Nelson Launches MSRA Roundtable

The Honorary Dr Brendon Nelson, Federal Minister for Education, Science and Training, officially launched the MS Research Australia's (MSRA) Roundtable on Friday 6th May at the Chatswood office of MS NSW. It represented the beginning of a new partnership between neurologists, MS researchers, the pharmaceutical industry and the MS community, all focused on accelerating research progress towards knowledge of a cause and cure for MS.

Professor Jim McLeod, who has pioneered MS research in Australia, and Graham Tribe, President of MS Australia, welcomed over 50 guests representing all parts of the industry and community. This was followed by presentations on where MS research is heading in Australia, from Dr Bill Carroll (Head of Neurology at the Sir Charles Gairdner Hospital, Perth) and a personal point of view from Sarah Ross-Smith, an MS Ambassador, who is also continuing her legal career at Blake Dawson Waldron.

The Minister, Dr Brendan Nelson, launched the Roundtable partnership with a speech that reflected his personal contact with MS. He welcomed the involvement of pharmaceutical companies, especially Biogen Idec and Sanofi-Aventis as principal partners with MSRA



and also acknowledged the key researchers including Professor John Pollard and Professor Graeme Stewart, both from Sydney University, who are advancing the knowledge of MS in the fields of Neurobiology and Genetics.

MS Research Australia is pursuing a goal to dramatically increase the funding of MS research in Australia and in that way aggressively pursuing research breakthroughs to benefit people with MS and to reduce the alarming increase of new diagnoses.

For further information on MSRA and to donate to MS research, e-mail: msra-info@msnsw.org.au, visit the website: www.msra.org.au or call 02 9411 4522.

Emotional Expression for MS

You are invited to participate in an exciting research study exploring the expression of emotion in people with multiple sclerosis that is being conducted in Sydney by Dr Julie Henry from the School of Psychology, University of New South Wales. Some people experience difficulties functioning as well as they'd like to in their work and social life now that they are living with MS. The aim of this study is to learn more about the possible causes of these difficulties and how they may be prevented.

Julie is looking for twenty participants who, if they agree to participate, will be asked to complete a number of questionnaires and short tests. The questionnaires will ask you about your emotions and how these influence your

day-to-day life. The short tests include tasks such as solving puzzles. The whole assessment will take approximately three hours and can take place in a mutually convenient location, such as an MS Society office at Lidcombe, Chatswood or Miranda, the University of New South Wales in Randwick or in your home. A small incentive of \$20 is offered in thanks of your contributions and to help cover any travel-related expenses.

If you are interested in finding out more about this study, please contact Julie on (02) 9385 3936. If there is no answer, please leave your name and telephone number and Julie or her research assistant Amy will phone you back within a day or two.

From the Desk of MS Busibody

Holiday adventures, 'Planning Travel with MS', by Bruce Mumford, page 6 (I had a sneak preview), brought back memories of my own globetrotting days, beginning in the seventies. Travelling with three little kids was full on and sometimes hard going with vaccinations, passports, customs and luggage. Later with the onset of MS, it became a bigger challenge. Later again my greatest conquest was my Europe with wheelchair expedition. It would all be too hard now, but the memories are forever. Bruce is spot on when he says do it while you can.

Now my favourite and only holiday getaway destination is right here at Byron Bay, where I am as I write. Unaccompanied, in my motorised wheelchair and backpack, I made the twelve hour CountryLink train/coach trip from Wyong to Byron Bay, thanks to the friendly and helpful CountryLink staff.

If you rely on home care, need a holiday, and if you find an accessible place to stay in NSW, it may be possible to get a home care swap deal. Look up home care website:
<http://www.dadhc.nsw.gov.au/dadhc/homecare.htm>

"Frequently asked questions"

"What do I do if I want to go on holidays and will still need assistance with my personal care?"

Advise your Service Co-ordinator as soon as possible of your intentions. If your holiday is within New South Wales and your accommodation has all the necessary equipment in place to provide you with a safe service, the branch can organise with a reciprocal service with the branch at your holiday destination."

In my case I stay in my daughter's wheelchair accessible house and hire a hoist and shower chair. The free pensioner CountryLink tickets add good value to the holiday. Now I'm a contented grandma, with memories of faraway places.

MS BUSIBODY ©

Mr Wisdom's Brain Gain

The Challenge Word, **PHENYLTHIOCARBAMIDE** was won by Elizabeth Watson of Tenambit, with a massive and very neat 2,484 words. Congratulations Elizabeth.

Next was Doreen Willis, of Eastwood, with 1,836 words, also very neat. Doreen was closely followed by Lorraine Mahe, of Towradgi, with 1,797 words. Well done, ladies.

Doreen has submitted a word she found in her 'Glaucoma News' magazine, which I thought you might like to try ...

HYPERHOMOCYSTINAENEMIA.

Doreen doesn't know what it means, and my 'Tabers Medical Dictionary' couldn't enlighten me either, (it does date back to 1975). If anyone can help, please let us know.

Because Doreen has probably already tried her word, my Challenge Word for this issue is **SUPERIMPREGNATION**, proving that it is a fallacy that you can't get pregnant if you are!

You can submit entries for either or both words.

The usual rules apply.....

- 1 Your listed words must be made up of four or more letters.
- 2 Use only letters from the Challenge Word.
- 3 No letter may be used more often than it appears in the Challenge Word.
- 4 No plurals, place names or proper nouns will be accepted.
- 5 And remember, it's a bigger challenge if you don't use a dictionary.

Mr Wisdom

Information & Education

SESSIONS COMING UP IN YOUR AREA (JULY – SEPTEMBER 2005)

NEWLY DIAGNOSED PROGRAM

These information sessions are aimed at people recently diagnosed with MS and their families and provide an overview of multiple sclerosis and programs offered by the MS Society of NSW.

Information Sessions

When: Monday 25 July 2005
Time: 6:30 – 8:30pm
Where: Phillips MS Centre
293 Mowbray Road, Chatswood
RSVP: TEL 9411 4522 by 20/07/2005

When: Monday 19 September 2005
Time: 6:30 – 8:30pm
Where: St George Leagues Club
124 Princes Highway, Kogarah
RSVP: TEL 9540 4544 by 14/09/2005

Information Telephone Conference

When: Tuesday 2 August 2005
Time: 7:30 - 8:30pm
Where: Telephone link-up for people living in country areas
RSVP: TEL 02 9646 0600 by 22/07/2005

Immunotherapy Update

When: Monday 15 August 2005
Time: 6:30 – 8:30pm
Where: Phillips MS Centre
293 Mowbray Road, Chatswood
RSVP: TEL 02 9411 4522 by 10/08/2005

Medical & Services Update

When: Wednesday 24 August 2005
Time: To be confirmed
Where: Lismore
Enquiries: TEL 02 6651 2505

Dealing with Change

When: Thursday 25 August 2005
Time: 10:00am – 12:00pm
Where: Studdy MS Centre
Joseph Street, Lidcombe
RSVP: TEL 02 9540 4544 by 17/08/2005

Medical Update

When: 11 August 2005
Time: 10:00am – 12:00pm
Where: Narellan Community Centre
14 Queens Street, Narellan
RSVP: TEL 02 9540 4544 by 5/08/2005

Dealing with Change

When: Wednesday 14 September 2005
Time: 6:30 – 8:30pm
Where: Phillips MS Centre
293 Mowbray Road, Chatswood
RSVP: TEL 02 9411 4522 by 9/09/2005

MS & BEYOND PROGRAM

Getting Your Wires Crossed:

Understanding Cognitive Changes

When: Thursday 14 July 2005
Time: 7:00 – 8:30pm
Where: Studdy MS Centre
Joseph Street, Lidcombe
RSVP: TEL 02 9540 4544 by 8/07/2005

Investing in Your Financial Future

When: Saturday 17 September 2005
Time: 10:00am - 12:00pm
Where: Studdy MS Centre
Joseph Street, Lidcombe
RSVP: TEL 02 9540 4544 by 9/09/2005

Tackling Fatigue

When: Tuesday 9 August 2005
Time: 7:00 - 8:30pm
Where: Southern Region MS Service
Ste 1, 28-30 Urunga Parade, Miranda
RSVP: TEL 02 9540 4544 by 3/08/2005

NEWS FLASH!

The videos and DVDs on Dr Jack Burks' key note address entitled "International MS Research and Management", which was presented at the MS Conference held in Melbourne last year, are now in stock and available for loan from the Library. Dr Jack Burks is Clinical Professor at the University of Nevada School of Medicine Reno, Nevada, and Chief Medical Office at the Multiple Sclerosis Association of America. You can order your copy for loan by contacting the Library by email library@msnsw.org.au or by phone 02 9646 0600.

Although every effort is made to avoid variation, session dates, times and venues may be subject to change. Please note that a nominal contribution fee may also apply.

Behind the Scene

It has been a busy three months for the MagScene Team. Garry has worked tirelessly from his office in Nowra on this issue and Elizabeth has been a fantastic support at the Chatswood office on Wednesdays.

In this issue we introduced an interesting and lively personal account of travelling with MS. We would love to hear your ideas for topics to cover in future issues of MagScene and invite you to send in your stories. Sometimes it is difficult to include everything we receive, but we do try!

We have missed Zanna's hands-on touch, although she is still very much part of the magazine. Zanna recently expressed her wish to share a few thoughts with readers:

" THANK YOU! THANK YOU! THANK YOU! for the letters, cards and emails. I want you to know how supportive and reassuring these have been, particularly on those "rough" days. Your support has brought me through the darker hours and things are now looking quite positive.

I have also moved home and am now residing at the Amity Grand at 18 Bardwell Road, Mosman (visitors by appointment are very welcome!).

Those of your who know my love of art will be pleased to hear that my first coach outing with Amity Grand was to the NSW Art Gallery. The Archibald Prize was disappointing.

More news next time, Zanna."

Next year marks the 50 years anniversary of the MS movement in Australia. The Society is making plans for how to best

celebrate the milestones and achievements since its foundation by Commander Ronald Alfred Phillips in 1956. We are looking for a celebratory theme for this extraordinary year and invite readers to contribute their suggestions by post to:

John Roubicek
Multiple Sclerosis New South Wales
Studdy MS Centre
PO Box 210
LIDCOMBE NSW 1825

You can also forward your ideas to John by email: jroubicek@msnsw.org.au or by phone: 02 9646 0600.

From all the team, happy reading!

Are you a new reader and is this the first time you have received an issue of MagScene? Would you like to subscribe to continue receiving each issue of MagScene by post at the full rate of \$20.00 or concession rate of \$10.00 for four issues each year?

The subscriptions we receive help cover some of the production and postage costs of delivering MagScene to readers' letter boxes.

You can also download MagScene from the MS Society website www.msnsw.org.au for no cost and can nominate to receive email alerts of future issues.

Contact the team by email magscene@msnsw.org.au or phone 02 9411 4522 for more information on subscription.

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