

Your Help is Needed!

In a modern society young people in aged care nursing homes is a “national tragedy”; yet this is the fate of 240 younger people with MS in NSW.

The solution is in the hands of our politicians. Do they know what is needed?

Quality of life of these people is the issue which cannot be reduced to financial arguments yet Government persists in arguing along this line.

The Multiple Sclerosis Society of NSW has launched a major campaign to bring to the attention of politicians and the media the plight of younger people with MS who are forced to live in aged persons' nursing homes.

There are currently about 240 people with MS who are living in nursing homes in New South Wales. Their average age is 49 and some are as young as 21. They live with people whose average age is 81.

They are forced to live in nursing homes because family and community care networks can no longer provide the level of care which they require and deserve to enable them to live at home.

The Society is examining a range of options designed to provide flexible accommodation support tailored to meet the individual needs of this group of people. It is examining all options, and has excluded none.

(Western Australia is widely regarded as the leader in innovative and progressive quality residential accommodation for younger people with high support needs. Their model is one which is under consideration.)

The major hurdle facing the society at the present time is the on-going cost of providing appropriate care to this group of people.

The NSW Society is able to make a significant contribution towards the capital cost of at least one pilot housing unit and it is confident that it can raise the money to build others in the future.

However, before the Society can even contemplate committing to expenditure of this kind, it must have a commitment from government that it will accept its responsibility and provide for the ongoing recurrent expenditure.

The Society estimates that the cost of maintaining one person in a fully supported unit is in the order of \$90,000 per annum.

The difficulty arises because the cost of providing nursing home beds for the frail aged is a federal government responsibility and the cost of providing support to the disabled is a state responsibility.

Australian Nursing Homes and Extended Care Association (ANHECA) reports that the federal government subsidises each nursing home bed in Australia to about \$70,000 per annum.

If this subsidy (currently paid to the aged care nursing homes) were transferred to beds in an MS Society facility, the difference needed to meet the recurrent costs would be reduced to \$20,000 per person per annum.

Additionally, if 240 people with MS were able to be moved from aged care facilities to young people specific facilities, the critical shortage of beds in aged care nursing homes in NSW would, at least in part, be relieved.

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NEW PUBLICATION

REQUEST FOR CONTRIBUTIONS

Publishers of a new Australian based international publication called "Illness: A Journal of Personal Experience", have asked us to pass on the following request for articles for publication.

"This journal was founded on the belief that there is a fundamental difference between disease and illness. While disease is confined by the physical boundaries of the human body, illness is how we, as human beings, experience that disease.

Our mission is to give illness a voice by providing a creative space for those who live with illness and

those who care for loved ones, strangers, and peers to come together to share their stories."

"We welcome contributions about illness from anyone in the form of fiction, non-fiction, poetry, songs, letters, paintings, illustrations, photographs, and other original compositions."

For detailed information for contributions contact:

Illness: A Journal of Personal Experience

P.O. Box 501

Newcastle West NSW 2302

Telephone: (2) 4927 5272 Fax: (2) 4927 5276

Email: illnessjournal@bigpond.com

HAPPY WINNER

As usual, I bought the last few tickets in the MS Society Mothers' Day raffle in May.

Imagine my surprise to receive a phone call from MS head office on 14 May to advise me that I had won the second prize of a night's accommodation at the Grace Hotel in Sydney. We had a time frame of up to six months to use the prize, but I decided to take advantage of the Sydney Film Festival screenings in June. The prize was so very timely because it was my partner's birthday the previous Sunday so that the weekend in Sydney became a belated birthday celebration.

Martin and I spent Saturday 16 June at the fabulous Grace Hotel. We drove up to Sydney from Wollongong and were very impressed with all aspects of the hotel. The King Superior Room was beautifully appointed with a very sophisticated but comfortable décor. We indulged in a full room-service breakfast on the Sunday morning. Staff were very pleasant and helpful, from reception to room service to valet service. The Grace is handy to most parts of the city, just a short walk to QVB, Pitt Street Mall or to the Rocks. We had only a five-minute walk to the State Theatre to see our film.

Having given up my full-time job last year (because of MS related problems), Martin and I are slowly adjusting to life on one income instead of two. It was great to be able to have a luxurious weekend away and not worry about breaking the bank. Thank you to the management of the Grace Hotel for making this prize available to the MS Society, and to the Society for conducting the raffle and drawing my ticket!

Pauline Reynolds

During MS awareness week Chief Executive Bill Northcote, who described the situation as a “national tragedy” appeared on national television with well-known younger person with MS, Nikolaos Kintominas, and Father John, the Administrator of the nursing home where Nikolaos is a resident. This was followed by radio interviews and press coverage.

People with MS can play an important part in this campaign.

MagScene asks that all PwMS contact their local members of parliament, the Prime Minister and his responsible minister, the Leader of the Federal Opposition, the Premier and his minister as well as the Leader of the State Opposition to make sure that they know that this matter will not go away.

Listed below are the names and addresses of senior politicians who should be bombarded with mail, faxes and emails about the issue.

It is only by bringing the matter to the attention of these decision makers and the general public that the matter will be resolved.

Dear.....

As a person with MS I am writing to bring to your attention the plight of more than 240 younger people with Multiple Sclerosis in New South Wales who through no fault of their own are forced to spend the rest of their lives in aged persons' nursing homes. Some of these people are as young as 25 years of age.

I do understand that the provision of suitable accommodation for the frail aged is a federal responsibility and that the provision of suitable accommodation for the disabled is a state responsibility.

While many nursing homes do a good job for the aged, it is not their responsibility to look after younger people.

They have the right to live with privacy and dignity in an environment designed to meet their needs rather than the needs of a community the average age of which is 81 years.

Surely the time has come for politicians on both sides of the political fence and at both state and federal levels to put their differences aside and work together to provide some justice and equity for this very disadvantaged group in the community.

Yours sincerely

The Hon John Howard MP
PRIME MINISTER OF AUSTRALIA
Parliament House
Canberra ACT 2600
Fax: 02 6273 4100
Email: (via) http://www.pm.gov.au/your_feedback/feedback.htm

The Hon Kim Beazley MP
LEADER OF THE OPPOSITION
Parliament House
Canberra ACT 2600
Fax: 02 6277 8495
Email: Kim.Beazley.MP@aph.gov.au

Ms Faye Lo Po' MLA
MINISTER FOR COMMUNITY SERVICES
Parliament House
Macquarie Street
Sydney NSW 2000
Fax: 02 9231 4318
Email: minister@community.nsw.gov.au

The Hon Bronwyn Bishop MP
MINISTER FOR AGED CARE
Parliament House
Canberra ACT 2600
Fax: 02 6273 4138
Email: Bronwyn.Bishop.MP@aph.gov.au

Senator Natasha Stott Despoja
LEADER: AUSTRALIAN DEMOCRATS
Parliament House
Canberra Act 2600
Fax: 02 6277 3235
Email: senator.stottdespoja@aph.gov.au

Mrs Kerry Chikarovski MP
LEADER OF THE OPPOSITION
Parliament House
Macquarie Street
Sydney NSW 2000
Fax: 02 9817 5885
Email: lanecove@parliament.nsw.gov.au

Senator Chris Evans
OPPOSITION SPOKESMAN ON FAMILY SERVICES AND THE AGED
Parliament House
Canberra ACT 2600
Fax: 02 6277 3695
Email: senator.evans@aph.gov.au

Mr Bob Carr MLA
PREMIER OF NSW
Parliament House
Macquarie Street
Sydney NSW 2000
Fax: 02 9349 4594
Email: bob.carr@www.nsw.gov.au

As your editor I encourage you to put pen to paper to help support younger people with MS.

Editor.

MAKING SENSE OF YOUR SENSES: MANAGING SENSATION IN MS

Have you ever felt like spiders or ants were crawling across your skin? If you have, you are not alone. Impaired or distorted sensation occurs in over 75 percent of people who have MS.

Our sensory system is important as it provides our body with a mechanism to monitor its internal and external environment. Our sensory system allows us to distinguish pain, touch, and temperature. It also helps us work out where our body parts are positioned in the space around us.

Sensation changes occur when one or more MS plaques appear in the areas of the brain or spinal cord that either carry information around our body about sensation, or play a role in interpreting that information. Like other symptoms in MS, sensation changes will be individual. Common sensation symptoms include pins and needles, numbness, tight bands, burning, itching, increased sensitivity, feelings of swelling, difficulty discriminating hot and cold and electric shocks.

If a person with MS has sensation symptoms they may not be able to feel how hard something is touching them. They may drop their coffee cup unless they are concentrating, or they may have difficulty coordinating their walking. Where there is loss of sensation, safety is also an important consideration. For example, a person may not be able to feel if the bath or shower water is too hot, or if they may cut themselves while completing cooking or maintenance jobs.

There are some simple strategies that can be incorporated into day-to-day life to minimise the risk of injury from sensation changes, and make life easier.

WHY DON'T YOU GIVE THESE A GO:

Regular checking of skin for cuts, abrasions or other sores

Using larger handles on suitcases, drawers and cupboards to give greater sensory feedback

Using utensils with wooden or plastic handles rather than metal ones

Using cups with lids and large handles

Using insulated coffee cups

Using a thermo-regulator that limits water temperature

Using a thermometer to measure water temperature

Using vision to assist in movements

Using rubber gloves when washing up, and

Wearing gloves or mittens in colder weather

From the desk of Occupational Therapy Rehabilitation Services, MS Society of NSW.

FOR ALL THOSE BORN BEFORE 1945

We are survivors! Consider the changes we have witnessed. We were born before television, penicillin, polio shots, frozen foods, Xerox, plastic, contact lenses, frisbees and the pill. We were before radar, credit cards, split atoms, laser beams and ballpoint pens. Before pantyhose, dishwashers, clothes dryers, electric blankets air conditioners, drip-dry clothes and before man walked on the moon.

We got married first and then lived together. How quaint can you be? In our time, closets were for clothes, not for “coming out of”. Bunnies were small rabbits and rabbits were not Volkswagens. Designer jeans were scheming girls named Jean and having a meaningful relationship meant getting along with our cousins.

We thought fast food was what you ate during lent and outer space was the back of the outdoor theatre. We were before househusbands, gay rights, computer dating, dual careers and computer marriages. We were before day care centres, group therapy and suntan parlours.

We never heard of FM radio, tape decks, VCR's, mobile phones, electric typewriters, artificial hearts, word processors, yogurt and guys wearing earrings. For us, time-sharing meant togetherness not condominiums. A chip meant a piece of wood. Hardware meant hammers and nails and software wasn't even a word. Back then, 'Made in Japan' meant junk and the term 'making out' referred to how you did in your exam. Pizzas, McDonalds and instant coffee were unheard of.

In our days, Grass was mowed, Coke, was a cold drink and pot was something you cooked in. Rock music was grandma's lullaby and Aids were helpers in the principal's office. We were certainly not before the different sexes were discovered, but we were definitely before 'Unisex' and 'Operations'.

We made do with what we had and we were the last generation that was naive enough to think you needed to have a husband to have a baby.

No wonder our kids don't understand us!

ACCESS TO MONEY

Sounds obvious, but many PwMS do not consider the need to maintain a back-up source of finance. The access to such funds was illustrated recently when assisting a 40 year old male during a period of no other income. The back-up funds were critical to his wife, the kids and the home loan company.

These back-up funds may be via a line of credit facility, a credit card, a savings account or a short to medium term investment such as shares, managed funds or term deposits. Long term investments, such as property, may be inappropriate as it is often expensive or impractical to access some of the funds.

Another, often overlooked, area can be superannuation. If your doctor classifies you as unlikely to return to work due to MS, you may be able to “cash” your super. This area depends on individual arrangements but may be worth a closer investigation. Recently I assisted a lady who could not return to work and managed to get about \$30,000 out of her superannuation fund, which certainly came in very handy during this period of mild distress.

There may also be some extra insurance built into the fund and you should check this thoroughly. It usually only lasts 30-60 days after finishing work and is often easily kept. Best option – ring the superannuation fund and ask.

Don't forget, life insurance is usually available for PwMS. If you feel you need it, you probably do need it. It is worth checking with your family to see if they feel you need it.

Tod Cameron, a PwMS, is a proper authority holder with AMP Financial Planning.

Licensed securities dealer, CAN 051 208 327.

He can be contacted on 02 9739 8620 or tcameron@insureinvest.com.au



FROM THE DESK OF MS BUSIBODY

When I ask my old “MS cyber-friend”, “How are you”?

She always replies, “Fine thanks”, and leaves it at that. When I asked her to ‘honestly’ describe her condition, her response looked pretty grim and desperate. She told me that she usually tries to spend more time laughing than whinging.

She explained, “My legs are paralysed, so circulation is kaput [I can wriggle second toe on left foot I millimetre at most]. Only one finger is in harmony with my brain, so that means I have problems with buttons, cutlery, pens, keyboards.

I have a ‘Vital Call’ device around my neck because I have fallen out of my w/chair a couple of times, [before I got the seatbelt].

Last week I fell off the loo ...don't laugh. I know all about ups and downs of MS but I still manage to have a sense of humour. I meet a new challenge nearly every day, but have a lot of help from home care, community nurse, MS society and ADDSI. They help me with personal care, housework, cooking, shopping, outings, home modifications and anything else that I can think of. Also my bladder is kaput and I have a catheter. My bum hurts from sitting on it 16 hours a day.

Hope you're still awake, you can sleep later! A couple more nasty ailments I won't tell you about now. You could say that I'm an old hand at MS. I was diagnosed in 1983 and now have chronic progressive MS.

Only one thing stops me, and that's heat. I go from 'slow' to 'stop'. To help with this I put in air/con. Apart from that, I'm fine, thank you.” She continued, “After that big whinge, I have to catch up with a lot of laughing.” She added, **“No, I don't enjoy bad health. And I'm not ready for a nursing home, I'm too busy enjoying myself. Anyway, I'm too young!”**

Ms Busibody

That married couples can live together day after day is a miracle that the Vatican has overlooked. *Bill Cosby*

Smiling is infectious, you catch it like the flu, when someone smiled at me today I started smiling too.

So, if you feel a smile begin, don't leave it undetected – let's start an epidemic quick and get the world infected

LAUGHTER IS THE SHORTEST DISTANCE BETWEEN TWO PEOPLE, IT BINDS US TOGETHER.

INFORMATION FORUM HELD ON 30TH MAY 2001

FOR PEOPLE WITH MULTIPLE SCLEROSIS, FAMILY MEMBERS + HEALTH PROFESSIONALS, HOSTED BY THE MS SOCIETY SOUTHERN REGION

An excellent day – professionally run and very informative. The Technology Park (Everleigh, Redfern) was an appropriate venue as it aims to be the center of technology and innovation. For those of us with MS who want to know as much as possible and keep up with the latest in MS management strategies, this was a must!

The Forum was opened by Carolyn Ball, Manager, Southern Region and Bill Northcote, CEO of MS Society of NSW.

KEYNOTE ADDRESS – PROFESSOR JOHN POLLARD, UNIVERSITY OF SYDNEY

We certainly had the expert here! Professor Pollard started with an introduction to MS, mentioning a number of other autoimmune diseases (such as diabetes and arthritis). Many MS topics were discussed in detail, here are a few:

Pathology of MS (I finally gained some understanding of the T cells opening the 'blood brain barrier' and the damage which can follow)

Prognostic factors

Electrophysical studies

Changes in therapy – the latest theories and test results on immunotherapy drugs stressing the importance of early treatment

The types and stages of MS and the signs of progression

Current thinking on re-myelination – positive results in animal tests.

This talk was accompanied by excellent slides which helped the non-medicos in the audience in their understanding of what many of us find a highly technical and complex subject.

I was impressed and relieved that Professor Pollard could add a number of good jokes – and as we all know, laughter is so good for MS. I've been to many conferences and never before have I seen a key note speaker break out into a quick step – excellent! This was an exciting and informative talk and I'm sure all PwMS and our helpers are very glad we have experts like Professor Pollard and his colleagues working so hard on our behalf to crack the MS mystery.

CONCURRENT WORKSHOPS:

1) For Health Professionals:
“Cognitive Changes in MS: Detecting, Understanding and Managing these symptoms in your MS Clients”

Speaker: Wendy Longley Senior Clinical Neuropsychologist MS Society

2) For PwMS and Families:
“Getting your wires crossed: Tips on Managing your Memory and Thinking Circuits better”

Speakers: Gordana Strumfin, Neuropsychologist MS Society, Megan Dephoff, Occupational Therapist MS Society

I attended the workshop for PwMS. As I have experienced significant cognitive changes and symptoms, I found this session really useful.

Gordana's paper was very detailed and we received excellent summary notes. She referred to cognitive changes affecting approx 40% of PwMS as the 'hidden symptoms' of MS and described how they are caused, cognitive exacerbations, changes over time, the fact that they don't come and go like some physical symptoms but can still fluctuate, etc.

Gordana noted the cognitive (thinking) changes most likely to disrupt functioning including:

Reduced thinking speed and concentration
Poor memory and new learning
Reduced problem solving, organization and initiation
Reduced flexibility and insight
Variable mood state

She discussed identifying cognitive change and explained the screening test (SEFCI) which can be done to determine level of impairment in MS. She explained the roles of the specially trained team at the MS Society who work in assessing cognitive damage and managing these frustrating symptoms (neuropsychologists, psychologists, occupational therapists, etc.).

The second part of this session was presented by Megan Dephoff. Her talk focused on Managing Cognitive Change. She described the rehabilitation services provided by the MS Society and the 'hands on' role of the Occupational Therapists who work with PwMS to develop individual and specific management strategies.

Megan's summary included many detailed strategies such as tips for planning and time management, paying

Continued page 7.

attention and staying focused, maintaining concentration, verbal rehearsal, visualisation (mental maps), use of mnemonics and rhymes, technology and external prompts, use of support networks and avoiding fatigue.

Megan selected a real life case study to illustrate what can be achieved in the management of cognitive change. We heard the story of Carol, an Architect who had experienced significant cognitive change which not only had affected her ability to run her business but also her self esteem.

Carol was assessed by the Neuropsychologists at the MS Society. She was experiencing many of the cognitive problems noted earlier by Gordana. Having established the extent of Carol's particular problems, Carol was referred on to one of the Occupational Therapists who visited Carol in her work place a number of times to gain insight into her specific work situation. Carol had prepared a written report herself to help explain her problems. Working closely together they were able to come up with various management strategies specifically suited to her needs in running her architectural practice.

Megan noted the importance of Carol's participation and perseverance in wanting to understand her cognitive difficulties and her determination to achieve success in implementing the management strategies.

It is clear that cognitive symptoms can be frightening, frustrating and difficult to explain to family and friends. But the good news is that we don't have to deal with these difficulties alone. I thought Gordana and Megan explained the subject really well and their obvious experience and sensitivity was well appreciated.

Thank goodness we have access to the specially trained professionals at the MS Society to help us stay on track (or get back on track.....).

The afternoon sessions were for health professionals. If the morning was anything to go by, I'm sure these sessions were also really informative. Thank you to all involved from the Southern Region in organizing this special day.

By a very impressed PwMS

LET'S TALK



I'm constantly amazed at how few PwMS have yet to advise the Society of their email address.

Although we have recently received many changed email addresses, especially those who used One Net as their ISP, there are many more that are on the Internet and therefore have an email that we don't know about. It is the intention, in the near future, for the MS Society to ask for email addresses when registering new PwMS. This will assist in more frequent communications. How we get the email addresses of those who have been with the Society for some time is a more difficult task. The more addresses we can get through MagScene (Let's Talk) the easier the task will become. Those who have given us their email address and know of others that haven't, please ask them to do so. This will assist us all.

Elizabeth Atkin, an outreach worker for the Northern Region, has been making up a list of Websites that she regards as useful for her clients. With Elizabeth's permission I repeat the list at the end of LET'S TALK.

The most recent "ads" for those PwMS in NSW who would like to have Webpals.

Coded Reference	451	Female
Age	30	
Lives in	Sydney South	
Years with MS	6	
Dated	May 2001	

I love arts and craft, reading, music, sport and SLEEP. Unfortunately being a new mum I have very little time for any of these activities. God gives me the strength to deal with MS, but being a mum to Aaron, my darling 5 month old baby boy is even a BIGGER challenge. I would love to hear from anyone who has both MS & CHILDREN. I could do with a few tips on being a parent with MS and how to SURVIVE bothHELP

Coded Reference	452	Male
Age	65	
Lives in	Singleton area	
Years with MS	6	
Dated	May 2001	

Continued page 8.

When diagnosed I had a slight “foot drop” and didn’t think much of it. Through ignorance and lack of advice I decided not to go onto Betaferon.

I managed to keep on at work until retirement (age 60 in the mining industry) and have been slowly deteriorating to the point where I am unable to walk without an aid of some sort. I have an electric scooter, a wheel chair, a rolator walker and a pair of Canadian crutches. As you can see I have just about every base covered. I have listed with the local tourist information center as a volunteer, and am struggling with this infernal machine (computer) I am on Epilim, Azathioprine and baclofen.

Coded Reference 453 Female
 Age 46
 Lives in Griffith area
 Years with MS 15
 Dated June 2001

I live in the country outside Griffith NSW, love all animals and have 3 children and 3 grandchildren. My husband has had to give up work and is now my carer. In May I had a continence diversion done. Would love a webpal.

Coded Reference 454 Female
 Age 24
 Lives in North Shore
 Years with MS 2
 Dated June 2001

I would love to have a webpal close to my own age. My MS has not affected me much and I work full time (12hr days!!) and proud of it. I have a few balance problems. Look forward to hearing from you.

Coded Reference 455 Female
 Age 48
 Lives in Sydney
 Years with MS 17
 Dated June 2001

I was diagnosed in 1993 after the birth of my daughter, but, looking back, my first incident was in January 1984. I am one of the lucky ones and have had relatively mild bouts. Fatigue, with its unpredictability and low levels of energy, is my greatest ongoing concern. Nevertheless, I am relatively healthy and active and would like to have the company of someone fit and active, who understands MS (but doesn’t want to talk about it all the time), to go for long walks in the country or city, or do the MS fund raising walk for next year.

Coded Reference 456 Female
 Age 28
 Lives in Sydney
 Years with MS 1
 Dated June 2001

My first symptom was optic neuritis in Sept 2000. My next was a loss of my legs which was accompanied by my diagnosis. I’ve recovered 95% from both attacks. I’m a food technologist and have a real interest in diet and MS after reading about the possible links. I do not currently take any immunotherapy, I have however had methylprednisolone twice. I go to the gym 3 times a week and dance classes weekly. I work in North Sydney. I’d love to have someone to talk to in a similar position.

Coded Reference 457 Female
 Age 50
 Lives in Sydney
 Years with MS 21
 Dated July 2001

I am a retired teacher and my interests include reading, cryptic crosswords, the theatre, and visiting National Parks. I am able to walk short distances but am using a wheelchair more and more and dreading the day when I have to stay in one all the time. Love to talk with someone in similar situation.

Coded Reference 458 Female
 Age 47
 Lives in Sydney
 Years with MS 4
 Dated July 2001

I would love to talk to anyone in a similar situation to my own. I teach part time and am going through a very messy and stressful divorce. I have 2 children who are 12 and 17. I use a cane to help me walk at the moment as falling down is a very bad look. I am on Betaferon.

If you would like to email any of the PwMS listed above please email me on garrya@msnsw.org.au and I will send the address. We cannot list email addresses in MagScene due to confidentiality issues.

- www.msnsw.org.au
- www.nmss.org
- www.msnews.org
- www.yale.edu
- www.quackwatch.com
- www.msnews.org
- www.ifmss.org.uk
- www.msaustralia.org.au
- http://medscape.com
- www.healthanswers.com.au
- www.mswebpals.org

Happy Surfing

GARRY

DOUBLE DOCTOR COUP



The MS Society's Medical Director, Dr Garry Pearce, discovered that the *International Journal of MS Care* had a shortage in its editorial staff of people with qualifications and skill in the psychosocial aspects of disease and health care. He therefore approached the Society's Senior Clinical Psychologist, Dr Gary Fulcher, to nominate him to the MS Care Board for consideration as part of the journal's editorial team. Considering that Dr Fulcher had vast clinical experience, two master's degrees in Psychology, a PhD and considerable research training and experience, Dr Pearce thought his colleague would be ideal for an editorial position. Dr Fulcher agreed to the nomination that was made in 2000 and on March 30 2001, the MS Care Board appointed him to the Editorial Board of the journal.

This appointment is significant for the MS Society of NSW as it is a recognition of the quality of staff it attracts, the growing emphasis on research it is fostering, and its role in the international world of MS. It is also a demonstration of the Society providing its staff with opportunities to assist in meeting its mission: **To advance the quality of life of people with Multiple Sclerosis, their family and carers, to educate the community and to find the cause of MS.**

Congratulations are offered to Dr Fulcher for this prestigious appointment and best wishes are extended to him in his quest to help to ensure quality research publication and to increase the emphasis on the investigation and integration of psychosocial factors in MS care.

TO RENT: ARCHITECT DESIGNED WHEELCHAIR ACCESSIBLE TOWNHOUSE!

A vacancy exists for a 3 bedroom townhouse fully wheelchair accessible, at the **Care'N'Co** Housing Co-operative in Minto (near Campbelltown). The housing co-operative consists of six architect designed and purpose-built town houses for people with disabilities and their families.

The vacant townhouse has 3 bedrooms and a separate garage and the preferred occupant would be someone using a wheelchair and who has a partner or small family to occupy the 3 bedrooms. The townhouses are about 5 years old, purpose-built for wheelchairs, spacious, private, and have very large bathrooms, storage for mobility equipment and fully accessible kitchens. There is a large shopping centre across the road and a wheelchair accessible train station about 15 minutes away.

The fortnightly rent is 25% of the Disability Support Pension, or if the person is working the rate is determined by the Directors of the Co-operative. It is not necessary for the person with MS to be already living in the area. The occupant would need to be prepared to participate in the "Co-Operative" by attending monthly meetings, being on either the maintenance or finance committee, and willing to contribute to the running of the Co-Op by sharing their skills (office work, finance, maintenance etc).

If you are interested please contact the Care'N'Co Secretary, Rosemary Gray on 9820 2299.

Robyn Faine Manager of Outreach Services

BOOK REVIEW *Dancing not Falling* by Sandy Lyons

Diagnosed with MS in 1991, Sandy Lyons was a secondary school teacher who had just returned from a hectic school camp when her vision was blurry and she could not see to read or drive.

It is now ten years down the road and her lifestyle has changed quite dramatically. Sandy thought she would like to share a year in her life with other PwMS or any other chronic illness.

The changes from a busy, productive city life, to a rural isolated life were found to be extremely difficult and frustrating. MS is so unpredictable and each day is an unknown. Sandy has to seize the day and live in the present. Difficult for one who was used to being involved in an enjoyable, hectic life.

Sandy loved being involved in school activities, directing or acting in evening theatre pleasures, studying to complete a degree on weekends and transporting two active children to weekend sport or parties.

Sandy says that MS is a difficult disease to handle. However with the help of her husband and friends she may have finally found that there is sunshine behind the shadows.

"Dancing not Falling" is a 12 month diary of learning to cope with MS. For a copy to be posted to you send your cheque or money order for \$9.95 to: C.D. & S.L. Lyons "Hesperia" Tooma NSW 2642

MR WISDOM'S BRAIN GAIN CHALLENGE



Cootamundra Champion, Helen Bording, has again led the field for last issue's challeng MYELORADICULODYSPLASIA.

Helen thought they were a lovely lot of letters!

She submitted 848 words, but ran out of time. Helen writes that the last issue was very interesting, "Spotlight" in particular, and she congratulates MagScene as it keeps getting better and better, particularly with the new format!

Lorraine Mahe sent 710 words, Clare Gemell of Roselands had 456 and that other gracious Cootamundra lady, Ronda Maher, submitted 362 words.

Thank you ladies for totaling your words, it saves me a lot of time, and my mental arithmetic isn't what it used to be. (age or MS, but alas, it's age I think)

Your Challenge this issue is
MUCOPOLYSACCHARIDE.

This should get your brain cells together and keep your fingers flowing with 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 must 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.

How did you go with your cryptic towns?

Here are a few more to muse over.

1. THE PRESENT TIME GIVES ONE ENCOURAGING CHEER
2. A COW'S MATE AND ME
3. THE ROYAL IS VERY ANNOYED
4. THE HAVEN INDICATES A DIRECTION (ON A COMPASS)
5. THE DAY AFTER TODAY
6. A CONFLICT IS SICK

Answers on page 16

Mr Wisdom

FAMILIES & CARERS SUPPORTING PEOPLE WITH MS

Expressions of Interest invited

"CARE TO LISTEN" is a pilot program funded through the NSW Department of Health and coordinated by the MS Society of New South Wales. It aims to provide peer support by telephone and/or visits to families and carers of people with MS.

We are looking for people who have personal experience or an interest in care giving issues and are willing to help other families and carers learn more about MS.

Contact Alex, Sharon or Marta on TEL: 02 9646 0600 or EMAIL: ahope@msnsw.org.au for further information and to express your interest in becoming a peer support volunteer for carers.

NEWLY DIAGNOSED INFORMATION & SUPPORT Newly Diagnosed Information Sessions

Monday 27 August, 6:30 – 8:30PM at Lidcombe.
Please contact Western Region MS Centre on TEL: 9646 0600 for details and to confirm your interest in attending.

IMMUNOTHERAPY & MEDICAL UPDATE

Wednesday 5 September, 12:00 – 2:00PM lunch time meeting in the city. Please contact Western Region MS Centre on TEL: 9646 0600 for details and to confirm your interest in attending.

MS & BEYOND: DESTINED FOR WELLNESS

Balancing Stress
Wednesday 8 August, 7:00 – 9:00PM at Chatswood.
Please contact Northern Region MS Service on TEL: 9411 4522 to confirm your interest in attending.

STEPS TO PHYSICAL WELL BEING

Saturday 15 September, 10:00AM – 1:00PM at West Ryde. Please contact Western Region MS Centre on TEL: 9646 0600 for details and to confirm your interest in attending.

TIPS FOR STAYING POSITIVE

Tuesday 9 October, 7:00 – 9:00PM at Lidcombe.
Please contact Western Region MS Centre on TEL: 9646 0600 for details and to confirm your interest in attending.

HOME ASSISTANCE 'N' DOMESTIC SUPPORT (HANDS)



HANDS is a commercial home care agency owned by the Multiple Sclerosis Society of NSW, servicing customers who are corporate, government or self funded. HANDS offer a range of services, including assistance with personal care, domestic assistance, respite care, 24-hour live-in care, sleepover care and assistance with transportation.

Currently HANDS provides assistance to clients in Sydney and many country towns throughout NSW including Bathurst, Central Coast, Dubbo, Gunnedah, Hunter area, Orange, Parkes, Port Macquarie, Mudgee, Tamworth, Tweed Heads, Wagga Wagga, Wellington and West Wyalong.

We would like to take this opportunity to introduce Judi McNally who has been appointed the new State Manager of HANDS. Judi's initial role is focused on the development of regional areas of NSW. Judi is currently establishing two regional HANDS offices, which will be based in Wagga Wagga and Coffs Harbour. Both these offices will be open in the next few weeks.

The Department of Veterans' Affairs has recently selected HANDS as an approved service provider for the new Veterans' Home Care (VHC) Program. Accordingly, HANDS is providing respite, domestic, personal care and gardening assistance to the Veteran community in country areas of NSW.

If you are interested in knowing more about HANDS you can visit our web site at www.hands.com.au, or please call Jamila, Jenny or Kerrie on (02) 9252 6144, or toll free on 1800 002 032.

A PRAYER FOR THE STRESSED!

Grant me the serenity to accept the things
I cannot change,
the courage to change the things I cannot accept,
and the wisdom to hide the bodies of those
people I had to kill today because they ticked me off.

And also, help me to be careful of the toes I step
on today as they may be connected to the butt
that I may have to kiss tomorrow.

L.I.S. Library & Information Services

The LIS currently has 28 copies of the "Paty" video out on loan - which has been a considerable task in cataloguing, processing and mailing each one. There are 7 people on the waiting list so we are hoping borrowers will view and return the videos quickly.

We also have available a new CD (for the computer) produced by MS Australia called "Seeking the cure. Providing the care". The minimum computer requirements are: -

Pentium 75Mhz compatible PC or higher, 16MB RAM, Win 95/98/NT, min 800 x 600 at 16 Bit colour; sound card; CD-ROM speed 4x or higher.

There is a site map on the back cover of the CD case which is needed to find your way around the information but the content is accurate, easy to understand and up-to-date.

Please contact the LIS or your local MS Centre or Outreach Worker for a copy of the CD or any of the other resources listed in this column.

Cate Dawson,
Manager, LIS, MSNSW

RECENT ADDITIONS TO THE LIS

ADAPTATION, PSYCHOLOGICAL

Coyle, P Halper, J. MEETING THE CHALLENGE OF PROGRESSIVE MULTIPLE SCLEROSIS – New York: Demos Medical Publishing Inc, 2001

BF 335 COY 2001 Bar code 001170

COMMERCE

Lakeland, K (ed) THE BUSINESS WHO'S WHO OF AUSTRALIA – 35th—Sydney: Dun & Bradstreet Marketing Pty Ltd, 2001 W 22 BUS 2001 volume 1&2 Bar Code 001184

HEALTH PROMOTION

Johnson, T Dephoff, M Roessler, C Sweeney, S. PUTTING IT ALL TOGETHER. A PRACTICAL GUIDE TO LIFESTYLE MANAGEMENT – Sydney: Multiple Sclerosis Society of New South Wales Australia, 2001 WA 590 MSS 2001 Bar Code 001188

REHABILITATION

Pryor, J (ed). REHABILITATION – A VITAL NURSING FUNCTION – Australia: Royal college of Nursing, Australia, 1999 Bar Code 001189

PATY BROADCAST HUGE SUCCESS

Almost 1,000 People with MS, their families and carers and health professionals attended the Donald Paty television broadcast on MS and its management as part of MS Awareness Week in New South Wales.

Professor Paty, an internationally renowned Canadian neurologist, spoke via a one-hour closed-circuit satellite television link to people with MS in all states and the ACT.

The broadcast linked people with MS, their families and carers and health professionals through the Rural Health Education Foundation television network.

The broadcast was also received in all other Australian States. It was the first time that people with MS in all parts of Australia has simultaneous access to the latest material on MS.

Professor Paty is Professor of Neurology at the University of British Columbia in Vancouver, Canada and is a regular presenter at international conferences and symposia. He has recently presented papers in China, Russia and the United States.

Professor Paty's address on MS and its Management was seen by people with MS, in places as diverse and far apart as Perth and Sydney and Cobar and Cairns. The Rural Health Education Foundation network, through which the broadcast was sent, has viewing sites in more than 450 locations in towns and cities throughout Australia.

A tape, produced by the Multiple Sclerosis Society of NSW, is to be replayed specifically for doctors on the Rural Health Education Foundation network in late July and copies of the tape are available to borrow from the MS Society library.

MagScene takes this opportunity, on behalf of PwMS readers, to thank all those who helped make this event such a resounding success.

Editor

PATY GOES TO TUMBARUMBA

A total of eight people attended the broadcast of Professor Paty's talk at Tumbarumba on June 7th. These included three professional people; the occupational therapist from Tumut, the district nurse Tricia Tarmo, and Marilyn Gilbert, who works in one of the offices.

There were two people diagnosed with MS and their three carers. All voted the broadcast excellent. Professor Paty proved to be extremely clear and easy

to follow. The three PwMS whom he chose to interview asked the type of questions any of us would have asked, making his talk extremely worthwhile and valuable. As Tumbarumba is quite isolated, we all congratulate the organisers for giving us the opportunity to view and take part in the day, a day that we don't often have like this out in the bush. Thank you all very much.

My only disappointment was that neither of the two doctors in Tumbarumba attended. However I have given them the paper work. Sandy Lyons.

MS AWARENESS WEEK IN THE ILLAWARRA

Several activities were undertaken in the Illawarra region to help raise public awareness of issues relating to Multiple Sclerosis.

Press Releases were sent to local TV and newspapers up to two weeks ahead of Awareness Week.

THURSDAY 31 MAY: Prime TV interview with PwMS Barry Nielson and his wife and carer Lorraine. Lorraine is also the new Secretary for the Illawarra Branch of MS Society and was able to get a plug in for some of our up-coming local events and to make a request for volunteer helpers.

MONDAY 3 JUNE: WIN TV interview with two PwMS, Rob Redman and Pauline Reynolds. Report placed emphasis on continuing employment of PwMS. This 90 second story was broadcast to all regions covered by WIN TV including Wollongong, Canberra and Wagga.

WEDNESDAY 5 JUNE: Wollongong Advertiser newspaper report on MS Awareness week and publicity for the broadcast on Thursday 6 June.

WEDNESDAY 5 JUNE: Guest speaker at Corrimal Rotary Club dinner meeting. Pauline Reynolds, as Secretary of Illawarra Council of PwMS, addressed the meeting on general MS information. Request was made for volunteer helpers for forthcoming Illawarra MS Branch events.

THURSDAY 6 JUNE: Outreach Worker, Jenny Crofts, hosted MS broadcast at Corrimal Community Centre. This event was well attended by approximately 30 PwMS and carers. Universally positive feedback was most encouraging.

QUEENS BIRTHDAY AWARDS

Dr Peter Sheridan AM has been awarded Australia Medal for services to people with MS. He was named an Officer in the General Division (AO) in the Queen's Birthday Awards. Dr Sheridan is a Board member of MS Australia and member of the Executive Council of the International Federation of MS Societies.

Mr Michael Stewart OAM President of the MS Society of South Australia, has been awarded an OAM for service to the community through the MS Society.

Mrs Zona Tripp OAM was awarded an OAM for her community work in raising money for charity. Zona is the Chairperson of the Dr Jeffery Tripp Committee which has raised over \$700,000 for the MS Society in the past 21 years. The Hydrotherapy Pool at the MS Society's Lidcombe Centre is named after the late Dr Jeffery Tripp.

MS OUTREACH WORKER

South Coast and Goulburn areas have welcomed Barbara Whitelaw, as the new ORW. Having completed her orientation she is now ready to take client referrals. Barbara's background is in counselling with experience in community-based work plus developing packages of services for people in need of domestic and family support. Barbara's hours are Monday 9 to 5, Tuesday 9 to 5 and Wednesday morning 9 to 1pm. Her email address is bwhitelaw@msnsw.org.au

The clients in the region will be notified by post in early August.

ILLAWARRA EASY ACCESS

A visitors' guide for people with limited mobility is a booklet that might be of interest to MagScene readers. It is a compact guide to 'accessible' accommodation and tourist attractions in the Illawarra area, a co-operative effort by Wollongong/Shellharbour/Kiama councils and tourism offices, with considerable auditing of access levels done by the Access Committee of Wollongong City Council. Tourism Wollongong website: www.tourismwollongong.com.au

Relevant websites/email addresses are quoted through the guide. Accommodation listings show a symbol for accommodation that requires assistance for wheelchair users, another symbol is used for full access. It has been audited (physically checked) by wheelchair users.

WORKING TOGETHER

Central Coast PwMS Council and MS Society Central Coast Branch members have combined their efforts in fundraising and in creating public awareness in MS at stands in major shopping centers. The financial year was rounded off with a raffle drawing at the AGM of the branch. Clem Payne was elected and welcomed as the new president, while his wife Sue was re-elected Secretary. Katie Booth, assistant Secretary, John Smith was re-elected Treasurer, with Frances Pavy and Jean Smith both vice presidents.

PROF DONALD PATY TV BROADCAST

On 7th June during MS awareness week was a huge success, reports Edith Morisset, Country Services Manager. Almost 1,000 people viewed the presentation in NSW at 42 hosted country sites and 4 Sydney sites. The Presentation showed a perspective on the diagnosis, management and research trends in MS. It was viewed on video at the CENTRAL COAST PwMS meeting where 50 people attended.

SHOALHAVEN MS BRANCH

The Annual meeting of the Shoalhaven MS Branch was held mid June at Osborne House Nursing Home. The retiring President Betty Henry congratulated the members for their willingness to assist PwMS in the area. The incoming committees is President - Betty Henry, Vice President - Phil Speer, Secretary - Beth Sanson, Treasurer - Marian Bone

CLARENCE VALLEY BRANCH

The Clarence Valley Branch advises that they will close the Branch after operating for over 36 years. PwMS and the Board of the MS Society congratulates it's Members on their amazing effort and dedication.

Readers are invited to e-mail contributions for 'Page 13 News' to the editor of MagScene at:

pwms@msnsw.org.au

or snail-mail to:

MagScene, PO Box 1246 Chatswood 2057.

COMMUNITY AQUATIC PROGRAM

Targeting clients with moderate to high support needs

We are bringing our Aquatic Team to appropriate pools in the areas below.

Six week Programs will be conducted for clients who feel they require 1 on 1 care in an Aquatic environment.

The Program will be conducted as an education for clients and carers so as to encourage further participation after the six-week period.

At this stage we are hoping to provide assistance with personal care and transport, and recruit volunteers to further assist with an ongoing program.

If you are interested please complete form below:

Aquatic Centre EXPRESSION OF INTEREST!

Name _____

Address _____

Phone _____

E-Mail _____

Please tick appropriate pool:

- Ripples, St Marys
- Cook-Phillip Park, College St, City
- Crawford Centre, Campbelltown
- Other (Please Specify - May be arranged if specific interest)

Preferred Day _____ Preferred Time _____

RETURN FORM TO OR ENQUIRES TO:

G Chamberlain
MS Society
PO BOX 210
Lidcombe NSW 1825

Ph: (02) 9646 0691
Fax: (02) 9643 1486
E-Mail: gchamberlain@msnsw.org.au

A LITTLE MIXED UP

Just a line to say I am living,
That I am not among the dead,
Though I am getting forgetful,
And mixed up in my head.

I am used to my arthritis,
To my dentures I am resigned,
I can manage my bi-focals,
But Christ, I miss my mind!

Sometimes I can't remember,
At the bottom of the stair,
If I'm going up for something,
Or I've just come down from there.

And by the fridge, so often,
My poor mind is filled with doubt,
Have I come to put food away,
Or have I come to take some out?

And sometimes when it's dark,
And my nightcap's on my head,
Am I just retiring?
Or just getting out of bed?

If it's my turn to write to you,
I hope you won't be sore,
I think I may have written,
And don't want to be a bore.

Just remember that I love you
And wish that you were near,
And now it's nearly mail time,
So I'll say "Goodbye my dear"

I'm standing by the post box,
With a face so very red,
Instead of mailing you my letter,
I've opened it instead!!!!

ANON

CLASSIFIEDS

FOR SALE

GLIDE SERIES 4 POWERED CHAIR

- Aqua Marine colour frame. R/H Control
- Pneumatic Front Castors, charger included.
- Originally purchased March 2000 for \$5500
- Asking \$3600 o.n.o.

Contact Marilyn on 0414 950 014

FOR SALE



ELECTRIC WHEELCHAIR

Quickie F55S, excellent condition, only used for 5mths. Power tilt, power recline backrest, seat belt, puncture proof tyres, swingaway tray, adjustable headrest, Dynamic Dx4 controller, 2x7.3amp charger. (Purchased for \$14,200)

PRICE \$9,000

REMOTE CONTROLLED DOOR OPENER

Previously used by wheelchair bound person for independent access.

PRICE \$250

MANUAL CEILING HOIST

Complete with two Self Aide hoists and enough rails for two rooms.

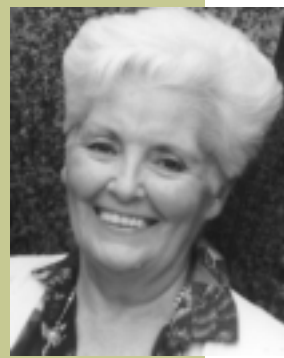
PRICE \$250

Contact: Maureen Grimaldi
Ph: (02) 4577 4229 Mb: 0409 774 229

PLANTS

Enquiries: Phil Thane
Phone: 9975 4029
Metro area only





It is not often that I ask you for help; seriously, we need support and help in lobbying the "powers that be" for a very good cause. There are 240 young PwMS in aged care nursing homes in NSW – this is a tragic situation. We ask that you and your family lobby by letter, fax or email on the plight of these PwMS.

A suggested letter and the essential addresses can be found on page 3. Let us flood them with mail to make our young people's needs felt. We would like to record the number of letters, email etc. that are sent so can you drop us a line or copy? I'll let you know how we fair. Thank you.

In the coming months you will receive through the post a special readership survey on your magazine, MagScene. We'll ask you what you like or dislike, what you would like to see more of, what type of information you need, medical, health, lifestyle, leisure, self-help, book reviews etc. All these types of questions; to find more about your needs in MagScene. As we are still working on this survey I will keep you up-to-date.

Maree Hamence phoned me regarding her daughter's birthday, her 21st. It seems that Maree wanted to make this one very special for Katie who is her carer, friend and loving daughter. It was the only way she thought that Katie would get a "thrill" and see how much she is appreciated and loved. **"Happy 21st birthday Katie from Mum"**.

As president of the Council of PwMS NSW it is time I stood down to allow some new blood into the Council. This important position needs to be filled by someone who lives in the

Metropolitan Sydney area because the President attends Society meetings, functions and should be free to fly interstate.

I ask you to write or call, nominating someone you know, or even yourself who might be suitable to represent us all at all levels of government and the Society.

With your Winter issue of MS Life there is leaflet concerning the MS International Federation International Conference 2001 to be held in Melbourne from 30 September to 5 October. It is an invitation to PwMS, carers and family to attend this once in a lifetime opportunity to hear world experts on all facets of MS. It isn't too late to register. If you are on the Internet see www.msaustralia.org.au

Thirty Three years ago the Tenterfield Branch

of the MS Society was formed to provide information and guidance to PwMS in the area. Today its main function is to raise funds to enhance the quality of life of those affected with MS. The new committee for 2001-2002 is President; Mrs. Margaret Baker, Vice President; Mrs. Shirley Pearse, Secretary; Mrs. Joyce Butler.

I'll see you in the spring!

The answers to Mr Wisdom's cryptic place names are:
1. Nowra 2. Bulli 3. Kings Cross 4. Sactuary Point
5. Temora 6. Warilla

Deadline for September/October issue is 30th August

MS INFORMATION LINE Freecall 1800 042 138

Mon-Fri 9.00am to 5.00pm. An info line only - Not a crisis line.

MagScene

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AMERICAN ACADEMY OF NEUROLOGY

Scientists and clinicians from around the world presented results of multiple sclerosis research at the **53rd Annual Meeting of the American Academy of Neurology (AAN)**, held in Philadelphia on May 5-11 2001. Here we present a summary of just a few of these results, with a special focus on clinical studies and trials of new and existing treatments. This is by no means inclusive of all the MS research presented at the meeting: Out of over 1450 presentations at the conference, some 190 were related to multiple sclerosis or MS animal models.

Combination Clinical Trials

In an effort to heighten the effectiveness of therapies for MS, researchers are investigating various combinations of treatments. All of the following trials are early studies using small numbers of people. Larger studies will be needed before we will know whether these combinations are safe and are more effective than single ingredient drugs.

Dr. Fred Lublin (New York) and colleagues treated 33 people with relapsing-remitting MS with **Avonex and Copaxone** concurrently, and found that treatment was safe (an issue that had been in question), warranting a larger trial to determine the effectiveness of this combination.

Dr. Thibault Moreau (Lyon, France) and colleagues administered **Avonex and azathioprine** (Imuran), an immune-suppressing drug, to 30 people with MS. They found the combination to be safe and tolerable, suggesting a need for additional trials to determine effectiveness. **Dr. Michael Kaufman** (Charlotte, NC) and colleagues enrolled 23 people who still had either relapses or progression during treatment with **Avonex**, and added oral **cyclophosphamide** or placebo. The results indicate that this combination is safe, with modest improvements in symptoms and in lessening the number of exacerbations.

Dr. Douglas Jeffery (Winston-Salem, NC) and colleagues administered **Novantrone**[®] (mitoxantrone for injection concentrate) to 7 people with MS who had been taking **Betaseron**[®] (interferon beta-1b) for at least 6 months. The combination caused no apparent adverse effects, and preliminary results suggested the frequency of new MRI-detected lesions decreased.

Other Clinical Trials

Findings were presented on several large studies extending our knowledge of the value of some currently available MS treatments. In a one-year, head-to-head trial conducted by **Dr. Luca Durelli** (Torino, Italy) and colleagues, 188 people with relapsing-remitting MS were randomly assigned to receive either **Avonex or Betaseron**. Results indicate that, during the second six months of the trial, Betaseron reduced relapse rates and reduced the appearance of new MRI-detected lesions and overall lesion activity more effectively than Avonex. The meaning of these results for longer-term clinical use is not known.

Dr. Kenneth P. Johnson (Baltimore, MD) and colleagues have followed 152 people with relapsing-remitting MS taking **Copaxone**[®] (glatiramer acetate) for 6 years, and found treatment continued to be safe and effective for a prolonged period. The investigators claim that the longer patients are treated, the more effective therapy becomes, and that delaying therapy increases the likelihood of disability.

Dr. Peter Rieckmann (Würzburg, Germany) and colleagues studied the safety and tolerability of **Rebif**[®] (interferon beta-1a) over four years in 445 people with relapsing-remitting MS. They found that the 44 microgram dose was as well tolerated and more effective than the 22 microgram dose. Using the same drug, **Dr. Andrea Paolillo** (Rome) and colleagues studied 55 people with relapsing-remitting MS and found that greater disease activity and MRI-detected lesion load before treatment predicted greater disease activity and brain tissue loss after 6 years of treatment – suggesting the need for early treatment.

Dr. Jeffrey Cohen (Cleveland) and colleagues presented results of the

“IMPACT” study of **Avonex**[®] (interferon beta-1a) in 436 people with secondary-progressive MS. (These results were announced in a Biogen corporate press release earlier this year.) Progression of MS in the Avonex group was reduced by 27% more than placebo, and the relapse rate was reduced by 33%. In a separate study, **Dr. Richard Rudick** (Cleveland) and colleagues evaluated results of using Avonex in 160 people eight years after enrollment in a study relapsing-remitting MS. Those treated with Avonex from the beginning had more favorable outcomes, with less progression of disability, compared to the expected natural history of the disease and to those who had been on placebo during the trial and were then switched to active treatment at its conclusion.

Early Clinical Trials

Researchers reported on several early, smaller studies (often called pilot trials) of medicines under investigation for the treatment of MS. Such pilot studies are usually done to test new concepts or to gather preliminary data that might help a scientist to decide if a new approach should be pursued in more depth.

Dr. Rhonda Voskuhl (Los Angeles) announced the results of her pilot clinical trial in which she administered the hormone **estriol** (which is elevated during pregnancy, when most women experience decreases in MS activity) to six women with relapsing-remitting MS and six with secondary-progressive MS. Treatment was well tolerated, and was somewhat effective in reducing lesions in relapsing-remitting MS, although not in progressive disease. Dr. Voskuhl concluded that further study of this hormone in people with relapsing-remitting MS is warranted. This project was funded through the USA National MS Society’s special targeted initiative on gender differences in MS.

Several groups looked at **methylprednisolone** treatment, focusing on new ways of using or evaluating the use of steroids normally used to treat exacerbations of MS. **Dr. Finn Sellebjerg** (Hvidovre, Denmark) and colleagues

found that treating 58 people during MS exacerbations with oral high-dose methylprednisolone significantly reduced MRI-detected disease activity. They also found that people who had active lesions at entrance into the study had a greater response to oral therapy. **Dr. Tania Kümpfel** (Munich) and colleagues found that monthly treatment with intravenous high-dose methylprednisolone (IVMP) reduced the number of active lesions by 49% in a group of 10 people with MS. **Dr. Robert Zivadinov** (Trieste, Italy) and colleagues found that IVMP every four months slowed brain tissue loss and the progression of disability in 81 people with relapsing-remitting MS. Dr. Joseph Frank (Bethesda, MD) and colleagues also found that IVMP to treat exacerbations decreased MRI-detected lesions for up to two months following treatment.

Valacyclovir is an antiviral medicine that is under investigation following previous studies suggesting a possible association between herpes viruses, particularly HHV-6, and MS. Two separate teams of investigators (from Århus, Denmark and New York, NY) tested valacyclovir in groups of people with relapsing or progressive forms of MS. Neither showed significant benefit on symptoms in most participants. One study found a subgroup of people with high disease activity (determined by MRI) when enrolled in the study in whom new lesion formation appeared to be reduced by the treatment. It is not clear, based on these studies, whether this drug holds potential to treat MS.

Dr. Arthur Vandenbark (Portland, OR) and colleagues administered a vaccine to alter immune cell activity, known as a “T-cell receptor peptide” vaccine, or placebo, to 106 people with relapsing-remitting MS. They found that the treatment was safe and well tolerated, and that immune cell activity was altered in a way that could suggest benefit in approximately one-half of those receiving the vaccine. Further studies are planned.

Dr. Michael J. Olek (Boston) and colleagues studied interferon-tau in a group of 31 people with relapsing-remitting MS. This immune system molecule is

similar to other interferons but is administered orally, and has been shown to have fewer side effects in rodent models of an MS-like disease. Dr. Olek reported no significant side effects, and is planning to study the drug's effectiveness in 100 people with relapsing-remitting disease.

Characterizing Primary-Progressive MS

Researchers presented studies on primary-progressive MS, which involves a progressive course at onset without prior relapses.

Dr. Giuseppe Santuccio (Milan, Italy) and colleagues studied people with primary-progressive MS in comparison to people with secondary-progressive MS (in which people begin with a relapsing course and change to a more progressive course later). They found less MRI-detected lesion activity in people with primary-progressive MS than secondary-progressive MS, but found more brain tissue damage in primary-progressive MS, as detected by novel imaging methods. They also found that the extent and severity of damage to the spinal cord in the neck area ("cervical" cord) is a main factor leading to disability.

Dr. Daniel Pelletier (San Francisco), a Sylvia Lawry Physician Fellow of the National MS Society, presented results on a study of nerve tissue damage in 23 people with primary-progressive MS, detected by brain imaging. They found that the loss of brain tissue overall in these people did not correlate well with areas of myelin (nerve fiber insulation) loss, indicating that the underlying mechanisms leading to brain tissue loss and myelin loss may differ.

Clinical and Laboratory Studies

Results of many basic studies related to multiple sclerosis were also reported at the meeting. **Dr. Guy J. Buckle** (Boston) and colleagues found that immune cells called CD8+ T cells are activated in people with secondary-progressive MS. These cells secrete a molecule, lymphotoxin, that has been shown to cause myelin damage, so this may explain the chronic destruction of myelin seen in people with this type of MS.

Four research teams presented findings

related to a possible role for the bacterium *Chlamydia pneumoniae* and multiple sclerosis. Several found some evidence of elevated immune system response to the bacterium, but no direct evidence that it plays a causative role in MS. An estimated 90-95% of the population has been exposed to this bacterium, and work to uncover a possible role of *Chlamydia pneumoniae* in MS continues.

Dr. Dorothee E. Chabas (Stanford, CA) and colleagues found that a molecule capable of aiding inflammation, called osteopontin, was abundant in samples of MS brain lesion tissues. In mice genetically engineered to lack this molecule, progressive MS-like disease rarely developed. The researchers concluded that osteopontin may be critical to the immune attack in MS, and may present a promising target for developing new therapies.

Dr. Wei-Ping Li (Newark, NJ) and colleagues, in a study funded in part by the USA National MS Society, found that several molecules known as caspases may be involved in the cascade of events leading to the death of myelin-making cells. The investigators suggest that in the future, the death of myelin-making cells in MS may be blocked by compounds that selectively inhibit the caspases involved.

June 2001 Research Bulletin, National MS Society of USA

<http://www.nationalmssociety.org/Research-2001Jun1.asp>

Note

We draw your attention to two inserts within MagScene

1: MS Treatment News which discusses the independent INCOMIN trial which compares Avonex® and Betaferon®

2: International MS Conference Leaflet which invites you to attend this 5 day conference in Melbourne from 30th September to 5th October. This is designed for everyone involved in any way in the "World of MS"

Editor

TOP MS HONOUR

AWARDED TO SYDNEY SCIENTIST

John W. Prineas MB, BS, FRCP Professor of Neurology, Department of Medicine, University of Sydney was awarded the USA National MS Society/American Academy of Neurology's 2001 John Jay Dystel prize for Multiple Sclerosis Research.

The \$US7,500 (\$A15,000) Dystel prize was established by Oscar Dystel and his wife Marion in 1994 to honor their son John Jay Dystel, an attorney, whose promising career was cut short by progressive disability from MS

Previous winners of this prize are Drs. Donald Paty (1995), Cedric Raine (1996), John Kurtzke (1997), Henry McFarland (1998), W. Ian McDonald (1999), and Kenneth Johnson (2000).

Dr Prineas began his medical training at the University of Sydney, and then travelled to London where he began to specialize in neurology. He went to the United States in 1967 as a postdoctoral fellow of the USA National MS Society, where he was mentored by Labe Scheinberg, MD – a pioneer in the clinical care of MS – and the eminent neuropathologist, Robert Terry, MD, at Albert Einstein College of Medicine in the Bronx, New York. In 1974, he became a Professor in the Department of Neurosciences at the University of Medicine and Dentistry-New Jersey Medical School, where he remained for 25 years.

Recently returning to Australia, he is now Professor of Neurology at the University of Sydney's Institute of

Clinical Neurosciences and Department of Medicine.

Dr. Prineas, who is both a neurologist and a neuropathologist, defined the pathology of MS with research papers that are now standard references in the field. He has devoted his career to understanding and explaining what happens to the brain and spinal cord after MS has wrought its damage to myelin and other nervous system tissues.

He was the first to describe – in the early 1980s – how brain and spinal cord myelin, the insulating material that speeds nerve signals, is destroyed in MS. He demonstrated that immune cells called macrophages engulf and absorb myelin. He also noted that immune proteins called antibodies participate in this breakdown of myelin.

In 1978, Dr. Prineas published a landmark paper showing evidence that myelin is repaired in MS lesions (damaged areas), and in 1993, demonstrated that this “remyelination” can normally occur, unless interrupted by disease activity. He showed that within a few weeks after the formation of a new lesion, the lesion is repopulated with new oligodendrocytes (myelin-making cells) and myelin can be repaired. Dr. Prineas was the first to demonstrate the ability of oligodendrocytes to regenerate in MS, and this work has stimulated many investigators to understand how this regeneration occurs and perhaps exploit this capability in the development of new therapies for MS.

The lift-out-and-keep **SPOTLIGHT on MS** supplement, which will appear in each MagScene, highlights current medical articles on MS in a condensed form.

Twice yearly, a **GP FOCUS on MS** newsletter is mailed directly to nominated GP's, Neurologists, Specialists and Health Professionals. If you would like your GP to receive this advanced clinical material, send your GP's name, address and phone number to MagScene: **PO Box 1246, Chatswood 2057**

The NSW Multiple Sclerosis Society is proud to be a source of information about MS. Comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

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