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argund & about

IN THIS ISSUE:**FOOTLOOSE FUNWALK****AWARENESS WEEK SUCCESS****DAVID ASHTON'S CRIPIN PLACE****TRAVELLING TO AUSTRALIA IN A WHEELCHAIR****SUMMER HAS FINALLY ARRIVED -****TIME TO TOP UP YOUR VITAMIN D**

EDITORIAL

This is our first newsletter being sent out on masse electronically. We hope that you enjoy it. All feedback is warmly invited and I look forward to hearing from you with your comments and suggestions.



Our **Awareness Week** was a resounding success with a lot of attention garnered by the wonderful ad campaign designed by the creative team at TBWA / Whybin to whom we give our grateful thanks. On Friday 4th and Saturday 5th September our fantastic street collectors manage to collect nearly \$37,000 across the wider Auckland area. Thank you so much to everyone that was on the streets on those days, we are very grateful to one and all.

The **Focus on MS** event on 18th September, run by the National Society including an interesting and diverse range of speakers which included Professor George Jelinek. A DVD of the presentations will be available very shortly and we may also be able to host a recording of the event on our website.

Our next event is the **Footloose Funwalk** which is being run in the Viaduct Harbour on **Sunday 14th November**. We have had a flurry of registrations in the last few days but have plenty of space so don't be shy – phone the office on (09) 845 5921 NOW and sign up for this fun event OR go to our website, www.msakl.org.nz and sign up there.

Cheers
Gary

JUST A REMINDER...

Letters to the editor, news, photos or anything you think may be of interest are welcomed. We can't promise it will be published, but your input is appreciated. Please contact the office on (09) 845 5921 or editor@msakl.org.nz

YOUR EMAIL ADDRESSES

We would like to keep all members updated with upcoming events and information which we feel would be relevant to you. Please email editor@msakl.org.nz and we will update your contact details.

FAREWELL NICOLA

In the middle of November we said a very reluctant farewell to Nicola Garland who headed off to start a new role with the Foundation of the Blind as Campaign Manager for the Puppy Week campaign. Nic had been with the society since the beginning of 2006 and had been involved in all of our successful events and campaigns since that time. She was instrumental in bringing in new ideas around direct mail campaigns and in running all of our key fundraising lunches and dinners over the last few years. Highlights for me include the Graham Sinclair dinner a few years ago which was great fun and more recently Peta Mathias' 60th Birthday Party which was an organisational feat of precise timing!!



Nic has already started her new role and will be sadly missed by all of our former colleagues here at the society and , of course, we wish her well in her new role.

Gary

Step, Stride, Strut, Wheel or Run around Auckland's Viaduct Harbour!

Footloose Funwalk

Sunday 14th November 2010, 10.00am
Waitemata Plaza, Auckland Viaduct

Hundreds of entrants with just one goal:
Supporting people with Multiple Sclerosis

What is the Footloose Funwalk?

- It's a fun event for all the family
- There are 2 options, a longer course of nearly 5km and a shorter one of approx 2.5km, you can register for either (routes will be included in the event pack)
- Entry fee: \$15 for non MS Auckland Region members
\$10 for MS Auckland Region members
\$30 for a team entry (4 + individuals)

What is Multiple Sclerosis?

- MS is a debilitating auto-immune condition affecting the central nervous system
- Symptoms can include: fatigue, blurred or double vision, numbness, pain, loss of strength, balance or co-ordination
- There are around 4,000 people with MS in New Zealand
- It usually strikes people aged between 20 and 40
- MS affects 3 times as many women as men
- There is currently NO cure



To register visit www.msakl.org.nz, email events@msakl.org.nz
or phone MS Auckland Region on (09) 845 5921



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FUNDRAISING AND VOLUNTEER NEWS

AWARENESS WEEK SUCCESS

During Awareness Week this year we had a fascinating and unique campaign running to raise awareness of the plight of people with MS and get the public talking.

We often take advantage of free space in magazines and our campaigns are used as fill-in adverts. The magazine publishers requirement is that we provide 'visually interesting' copy and this years campaign certainly fell into that category. We are extremely grateful to Jenny MacMillan one of our long-term supporters and the creative team and TBWA / Whybin for supporting us once again.

You might also have heard the radio ads that were running at the same time across the Radio Network stations in Auckland. Again these radio slots were provided free of charge to us and we acknowledge the support of the TRN.

Our street appeal on Friday 4th and Saturday 5th September was a triumph, despite the fact that we were not able to cover all of the locations with collectors that we had received permission to collect at. We are so very grateful to everyone that took to the streets and rattled buckets on our behalf again this year.

Thank you so very much for all of your help and assistance. Once again this year we managed to collect over \$37,000 which is a fantastic effort!!!



DONATION FORM

I would like to subscribe to the MS Society of Auckland & the North Shore Inc (\$40 per annum)

I would like to donate: \$25 \$50 \$100 Other \$ _____

Payment method: Cheque Visa Mastercard
(please make cheques payable to the Multiple Sclerosis Society of Auckland & the North Shore Inc)

Card No: _____ Expiry: _____

Name on Card: _____ Signature: _____

Title (circle one): Mr / Mrs / Miss / Ms

First Name: _____ Surname: _____



Address: _____

Suburb: _____ City: _____

Phone: _____ Email: _____

For details about leaving bequests or further information on how you can help MS Auckland Region, please contact the office on (09) 845 5921

PHONE 0900 YES 2 MS

Call 0900 93 726 to make an automatic \$20 donation.

Please ensure you have the account holder's permission.

FUNDRAISING GOT AN IDEA?

Do you have a great idea for fundraising? Know anyone who may be able to help out? Perhaps donating or subsidising an event or prize or just their time.

Contact the office or email gary@msakl.org.nz

FIELD WORKERS UPDATE

FROM ALLISON - RODNEY / EAST COAST BAYS

It seems we've been through a narrow squally tunnel to get into Spring but thank goodness it's here at last. I now have another delightful granddaughter, born 1st September so she definitely heralds a new season and is doing really well. It's very special to live close by and watch her change and develop and of course have lots of cuddles. Some of you receive the Family Care magazine that comes quarterly. It's an excellent free magazine with heart warming stories, tips, products and much more. We have a few spare copies in the office if you want to view it or you can find out more and sign up at www.carers.net.nz or phone 0800 777 797. Enjoy Spring with all the wonderful new growth and sunshine.



FROM BEA - MID AUCKLAND

Hi everyone. Yet another newsletter bites the dust, does not seem that long since last one. We had our annual Field Worker training this month and it was good to connect with other field workers nationally and to hear some excellent speakers on a range of topics related to MS. Some of you may have also gone to the Focus on MS the following day in central Auckland. Don't forget to take the opportunity to get out there and enjoy the warmer weather and to take part in some of the wonderful groups and activities available. I am looking forward to buzzing by some of you in the next few months.



FROM DIANE - NORTH SHORE

September has been a busy month with the Annual MS Awareness Week appeal, Field Worker Study Day and the MS in Focus Information Day. It was great to catch up with Field Workers from the other regions and hear updates about Multiple Sclerosis. It's great to see the spring, get out there and enjoy the sun. Another thing to do to feel good is to come along to the Millennium Pool Group every Wednesday from 10.30 to 11.30am at Mairangi Bay. They are a friendly group and have a lot of fun. Ring the office on (09) 845 5921 to find out more. Enjoy the warmer, sunnier weather and if you haven't heard from me for a while do give me a ring.



FROM DIANNE - SOUTH AUCKLAND

Isn't it nice knowing that spring is here and hopefully the sun will follow! It seems to me that we have had a long, wet winter. I'm looking forward to getting some Vitamin D3 the natural way! I have read recently about the latest therapy idea on inclining your bed that was written in the 'New Pathways' magazine July/August 2010. It sounds interesting and may be worth trying. Mechanical engineer Andrew Fletcher has come up with the idea that people with MS should raise the head end of their beds by 4 to 8 inches to help blood flow better and so improve MS symptoms. If you would like to read this interesting article then go to www.msrc.co.uk/downloads/npwm_2010_0062.pdf. Happy reading.



FROM GEORGA - WEST AUCKLAND

Quality of life can really be enhanced by having some type of hobby or activity that you enjoy doing. Something that you can get immersed in and lose track of the time. For me I enjoy gardening and playing the drum. I have visited clients with varied hobbies including wine making, reading, piano playing, watching movies, writing, knitting, listening to music and growing vegetables. Why not think about spending some more time on a special interest, or even starting a new hobby. Hobbies can be solitary or there may be a club or group who share your interests that you could join. Go for it!!



FROM GLEN - CENTRAL AUCKLAND

Here's a resource worth looking at and which many people with MS find very helpful and interesting. It's the glossy and colourful 'New Pathways' magazine put out by the Multiple Sclerosis Resource Centre (MSRC) in the UK 6 times a year. It's written for and by people affected by MS. You can obtain a complimentary copy (only paying the postage) or you can download it (and any back copies) for free. (It's also available on audio CD). Friendly, informal, informative and spectacular layout are some of the comments received for this magazine. Visit www.msrc.co.uk and click on New Pathway Magazine, email info@msrc.co.uk or phone +44 1206 505444



MORE NOTES FROM THE FIELD

MS SEMINAR

At the MS Seminar in September the highlight of the day for me was Professor Jelinek's presentation which touched on aspects of research on medications, CCSVI and Swank research in the 1940's. He was looking at the integrity of research and the factors that surround the outcomes and stated that due to a variety of factors the result reliability varies. Research of course is his field and what he said made a lot of sense as he presented the facts that surround research. After a long hard look at all this he ended by stating his unequivocal support on the side of a non saturated fat diet, meditation, exercise and VitD3. I really appreciated his openness and honesty given from the heart. For those who don't have the website it is: www.overcomingmultiplesclerosis.org. He is always updating his website with new info and it is well worth visiting often.

Allison

LOW DOSE NALTREXONE

A number of people have asked me where they can get Low Dose Naltrexone (an immune system booster) dispensed. Get your prescription from your GP and contact Pharmaceutical Compounding NZ Ltd, phone (09) 442 1727.

Diane

GET SOME VITAMIN D

After such a long, wet winter many people will have depleted Vitamin D levels so it is important to catch as much of the sun as you can in the warmer months (also look at oral supplementation). Just 20 to 30 minutes with as much exposed skin as possible can be therapeutic. Leave the sun block off but be careful not to fry during the hottest part of the day (between 11am and 3pm).

Diane

ANOTHER GREAT RESOURCE

The 'Headline' newsletter put out by the Neurological Foundation of NZ is a very interesting newsletter on brain research covering neuro science, the latest in brain research info, management of neuro symptoms etc. Membership subscriptions are only \$5 a year and you will receive several newsletters as well as access to helpful information. Visit www.neurological.org.nz or phone (09) 309 7749.

Glen

SNIPPETS AND WEBSITES

MEDSAFE

Medsafe is a very informative website that you can visit for a great deal of information on the regulation of medicines and medical devices which are currently available in New Zealand. There is also information on the safe use of medicines, consumer medicine information, classifications of certain medicines, unapproved medicines, clinical trials, regulatory issues and much more.

Please visit www.medsafe.govt.nz

MOBILITY FOR INDEPENDENCE

Are an Auckland based company who are specialists in their field of vehicle modifications. They concentrate on products that make travelling, driving and transferring into vehicles as simple as possible.

Mobility for Independence provide mobility aids, ramps, scooter and wheelchair lifts, driving aids and other products to help you retain your independence. You can visit their website or contact them for any current specials they may have.

Please visit www.mobility.co.nz or phone (09) 445 8401.

EMPLOYERS' DISABILITY NETWORK – EDN

Is a not-for-profit network of organisations sharing best practice on working with disability in all areas of business. Their overall mission is to create and promote a culture of inclusion within the business and public sectors, to assist business and public sectors to become disability confident, to recruit and retain disabled employees and to better serve disabled customers. Their website www.edn.org.nz provides a wealth of resources and information, there is also an opportunity for information relating to courses, events and conferences.

For more information or to join EDN as a member please contact them on (04) 978 4142 or email info@edn.org.nz

MULTIPLE SCLEROSIS RESOURCE CENTRE – MSRC

Is a website that provides a range of useful resources including drug research, new discoveries, MS knowledge research, diet research and general information related to MS.

Please visit www.msrc.co.uk to view the latest research information.

For more information on these articles contact the MS Auckland Region office on (09) 845 5921 or email info@msaki.org.nz

MOOSE GROUP TRANQUILITY RETREAT 2010

5-7 November 2010

The Moose Group was formed to take a light-hearted proactive approach to managing MS. The group is open to anyone with MS and their partners.

This years retreat is a truly spectacular and tranquil setting. The Wellesley Country Park is an exquisite lodge based in beautiful native bush in the Akatarawa Valley, Upper Hutt. This venue has ample accommodation and fantastic programme spaces.

A number of accommodation choices are available – from affordable bunk beds to paying an extra premium for the ensuite 'Riverside' facilities or cottages. Please note: bunks have a mattress – but you'll need to bring your own linen, or sleeping bag and pillow.

Food

Fully catered to satisfy hunger for tasty, healthy food. All breakfasts, lunches and dinners will be provided – as well as plunger coffee, tea and fresh fruit.

Children

We have an experienced child minder who can supervise children, with art classes and activities to keep them happy!

Travel

If you need travel assistance, contact another attending Moose Group member or the organiser to try and organise a lift.

Price

The following prices include all meals, workshop activities, individual massage, hot stone and much more!

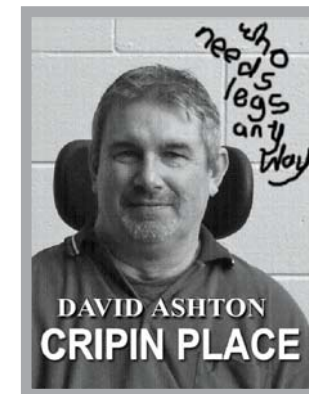
Per adult for the entire weekend:		Children's prices for weekend:	
Cabin Room	\$160	Under 5's	Free
Cottage Room	\$190	5-12's	\$70
Riverside Suite	\$220	Over 12's	\$110

Plus a 50% subsidy is offered for people who have MS and are working part-time or not working (cabin rooms only).

For more information or if you have any questions please contact the retreat coordinator Roisin King email roisinking@mac.com or phone (04) 973 3874.

I'M PUBLISHED - DAVID ASHTON'S CRIPIN PLACE

After two years painstaking work recollecting my experiences and recording them in a readable story, I have now been published electronically. Depending on demand printed copies will be available at a later date, but the adventure is available to view now. Using a headmounted laser keyboard, writing this book has been a challenge in itself, not to mention the chiropractor fees! Presently I am raising awareness of the book's existence and wonder if you can help in some small way?



Cripin Place was published on Thursday 21st October as a multi-format ebook at Smashwords. As many of you know, the book is about my experiences living with MS since my return to New Zealand. I hope you'll take time to check it out at Smashwords, where you can sample the first 50% of the book for free.

Reviews:

David's life story is not for the faint hearted, feeble minded or humourless. This is an expose on how life is for persons living with MS, dependant on the vagaries and mindless inconsistencies of State funded care and oft times compassionless Bureaucracy. A gripping and Roller-Coaster read, you will find yourself outraged, humbled, overwhelmed, angered, nourished and inspired in turn, sometimes on the same page. – *Christina Treneary, North Shore Community Advocate*

Dear David, I absolutely loved your book! Your wondrous spirit, joy, humour, courage and patience is so powerful that one forgets the incredible limitations that is the daily reality. – *Your Number One Fan, Philna*

I bought it this morning and am already almost finished, it is a very good read. I've burst out laughing a couple of times causing my flatmate to look across at me like I am crazy. – *Nicki*

Please help me spread the word. Take a moment to forward this information to everyone you know, and ask them to do the same? Thank you for your support!

David Ashton – Author of *Cripin Place*

To sample a portion or to purchase *Cripin Place* visit:
www.smashwords.com/books/view/27454

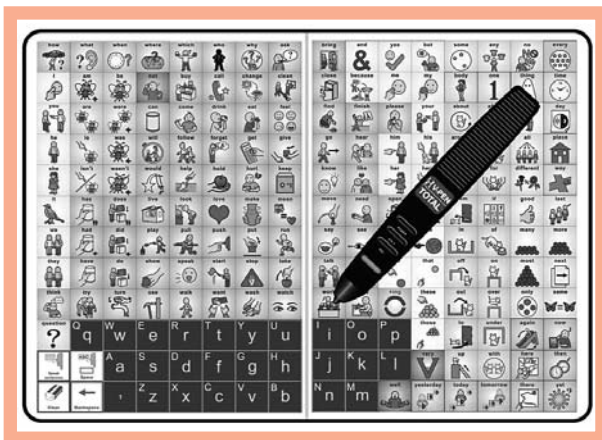
VOICE-PEN MAGIC

Imagine printing a communication board and have each symbol speak! With just a simple touch with a V-Pen, your symbols come to life with speech, sound and music.

Voice Symbol

Voice Symbol™ software provides a quick and easy way to create interactive communication boards and books that can be printed on a standard colour ink-jet or laser printer.

Simply choose the grid size required for your specific communication board, then select and place symbols into the cells and print!



These symbols may contain a spoken word, an MP3 music file or any other sound of your choosing and spoken or played by touching the symbols themselves with a V-Pen. If a number of symbols have been selected to create a sentence, the whole sentence can be spoken as a single unit by selecting the 'speak' function. As the cells are not limited to vocabulary, but can store any sound file, each cell could contain a favourite piece of music, turning your page of symbols into a jukebox! The possibilities are endless!

Voice Ink

Voice Ink is a programme which imports any Microsoft Office document (2003 and above) and converts it into a form which can be recognised by the V-Pen. Voice Ink embeds hidden codes inside the printer's ink which creates the text so making it possible to have any text spoken aloud.

Who Can Use a V-Pen?

- People who use a word or spelling-based system to communicate.
- People who have a wide range of disabilities such as Cerebral Palsy, Autism, Downs Syndrome, Dyslexia, Motor Neurone Disease, Stroke, or Multiple Sclerosis to name a few.

- Used by people of all levels of ability and literacy.
- Any age, from pre-school, through school / college, to adults with acquired disabilities.

Features

Light weight
Extremely portable
Very discrete
Durable and reliable

Uses synthesised and digitised speech
Label memory cells for easy communication
Easy to learn and simple to use
Long battery life (2 AAA's)

Technical Specifications

Processor: AF3372
Optical Head: Red Infrared
Size: 17.5cm x 2.6cm x 2.6cm
Weight: 41g (without battery)

Memory: Micro SG Card (2Gb – 4Gb)
Battery: Two 1.5v AAA batteries
Auto-Power Off: After 3 minutes of non-use

If you wish to see a demonstration or to trial the V-Pen please contact Zabonne Ltd Tel: **(09) 836 8876**, Toll Free: **0800 351 151** or email: sales@zabonne.co.nz

MESSAGE FROM CCS DISABILITY ACTION

We're just sending a quick note out to let people know that there will be a small increase in the fees for new and renewed mobility parking permits from 1 October 2010. This will cover the GST increase that will be effective from this date and will also support the ongoing work we do to manage the mobility parking permit scheme. From 1 October the following fees will apply:

Long term permit [Five year term \$50.00 - GST inclusive]

Short term permit [Up to 12 months \$35.00 – GST inclusive]

Following on from the survey we did last year, we will be making a number of improvements to the scheme, including looking at ways to reduce the illegal use of mobility parking places. If you would like to keep up to date with news and issue around mobility parking, sign-up to our eNewsletter via our website www.ccsdisabilityaction.org.nz.

Kind regards,
Peter Wilson
Disability Partnership Leader, CCS Disability Action – National Office

MY STORY

TRAVELLING TO AUSTRALIA WITH MS AND A WHEELCHAIR...

Ian and Christine Hallett recently returned from a two week holiday in Northern Australia. Many people visit the Eastern Seaboard; Melbourne, Sydney and Gold Coast, but not as many visit the tropical north.

The holiday was in the July school holidays as Christine is a secondary school teacher.

Ian was diagnosed with Progressive MS 18 years ago, he sold his car (an MGB) about 4 years ago when his legs stopped working correctly, but he can still walk about 25 metres with the aid of crutches.



The itinerary was Auckland to Cairns & Port Douglas, Darwin, Kakadu National Park. The Ghan to Alice Springs, Ayres Rock, to Adelaide, Melbourne & Sydney for a day each to catch up with friends over dinner, then home to Auckland.

The Wheelchair

Until last Christmas, the only wheelchairs Ian had seen required a specially modified van to transport them. At Christmas Ian met a gentleman from Australia whose wife required a wheelchair after a stroke. It was foldable and able to be carried in a Holden Commodore station wagon.

Another foldable wheelchair was seen at the Ellerslie Racecourse in February, which could fit in an ordinary saloon car. The chair (made by Puzzle in U.S.A) broke into three parts, the base, battery, and the seat which folded, similar to a deck chair.

The Disability Resource Centre in Royal Oak was contacted, and alternates researched. A 'GO' wheelchair was obtained. This chair has the added advantage that the Joystick/Controller on the right hand armrest can be unclamped and removed. When the chair was checked in at airports, it was removed and put with Ian's 'carry-on' luggage, thus preventing damage. Note that the battery

must be IRTA approved (International Regulations Transport Association) to make sure it is safe to be transported by aircraft. The chair has 2 levers at the rear of the chair which disengage/engage the drive. As the brake is engaged on the removal of the power, it was simple to disengage the drive/brake and manually move the chair, then engage the drive/brake when parked in position to be transported.

The weight of the wheelchair is 47 kg, when dismantled, Base = 25 kg, Seat = 20 kg, Joystick Controller = 2 kg. Easy to manoeuvre, and able to be easily handled by freight staff. The Australian freight staff strictly enforce the 20kg weight limit, even on the train!

Heat

Even in winter the temperatures in Darwin and surrounding areas are in the low 30's, most places are air-conditioned. The temperature in Northern Queensland was in the mid 20's, so the fatigue was not a problem. We found that central Australia was cold, (approx 15 degrees) and wet, not hot and dry as expected.

Methods of Travel:

Air

Trans Tasman was with Air New Zealand, Australia Domestic was on Qantas. Air New Zealand have aisle wheelchairs on all international flights. Qantas have aisle chairs to assist disabled passengers to their seats when boarding/d disembarking. The longest flight domestically was 2.5 hours Cairns to Darwin. On board facilities not tested. All airports had air bridges, except the small Airports of Alice Springs & Ayres Rock, where they used a platform raised by a fork-hoist.

Car

We hired a rental car in Darwin, mainly to see the Kakadu National Park, but it was useful getting around Darwin. The car was a Toyota Corolla saloon. It worked well, the suitcases went in the boot, the chair with separate seat and base on the back seat. Occasionally Christine requested the help of a passerby to help her load the chair base & seat into the car.

Bus

The 20 seat coaches used by shuttle operators at airports usually towed a luggage trailer. The chair could fit into these completely assembled. The 60 seat Mercedes coaches used at Ayres Rock were also able to load the complete chair directly into the side luggage lockers.

Rail

The train 'The GHAN' took us from Darwin to Alice Springs, a 26 hour journey, which included a 4 hour stop at Katherine. This enabled us to take a tour by boat up the spectacular Katherine Gorge. A wheelchair was provided at the gorge for transferring from the bus to the boat.

The GHAN had an aisle chair which was used when transferring, especially to the dining car, the meals were excellent.

There are 3 classes on The GHAN, Platinum has a double bed, Gold has bunks and Red has aircraft style seats. There is also Gold Superior, which has double the compartment space, which is what we booked.

Note that July, especially the school holidays is peak season. We booked 3 months ahead before the journey, and booked the last compartment. Disabled compartments are available, but need to be booked well in advance.



Boat

In all there were 7 Boat trips.

The Quicksilver boat which took us to the Outer Barrier Reef, it was very similar to the Waiheke ferry, and the chair was able to be driven up the ramp onto the boat. We were invited to use the staff toilet which had hand rails, and more space than the passenger facility. We also used the toilet as a changing room before we went snorkelling. The staff were very helpful.

To get into the Glass Bottomed Boat was a challenge, with its narrow steep stairs, but with the help of staff this was easily achieved. The effort was well worth it, even though the coral was lacking colour because of the overcast day.

The boat at the Yellow Water Billabong, and the Katherine Gorge were of the same design, with 12 rows of seats, 2 seats each side with a central aisle. They were easy to board with a ramp onto the front of the boat.

The sunset dinner cruise in Darwin was excellent, on a classic schooner the 'Alfred Nobel'. The access was down a ramp, the food, especially the fresh seafood, is to be recommended

The Jumping Crocodiles in the Adelaide River had a larger version of a River Boat. Two of the photos show the access to the boat and Ian being assisted from the boat by two of the staff.

The Daintree River required a walk of about 200 metres, Christine took this cruise, while Ian did some additional sightseeing.

Accommodation

All Hotels and Resorts except The Coolinda Lodge, in Coolinda, in the centre of the Kakadu National Park had disabled rooms. The staff at Coolinda were most helpful, providing a plastic chair for showering and a manual chair for transfers.

Bathrooms were usually Tiled, with care needed to be taken on the slippery floor, but this meant 'walk in' showers.

Summary

A fantastic holiday, the wet weather in Central Australia being the only low point. Except for a restaurant in Melbourne, a shop in Darwin and the Coolinda Lodge Chalet, all places had Wheelchair access. Both staff, and the general public were most helpful in providing assistance when required.

A wheelchair used on Holiday in the northern part of Australia is relatively trouble free. A holiday in that part of the world is to be encouraged, don't let mobility problems discourage you.



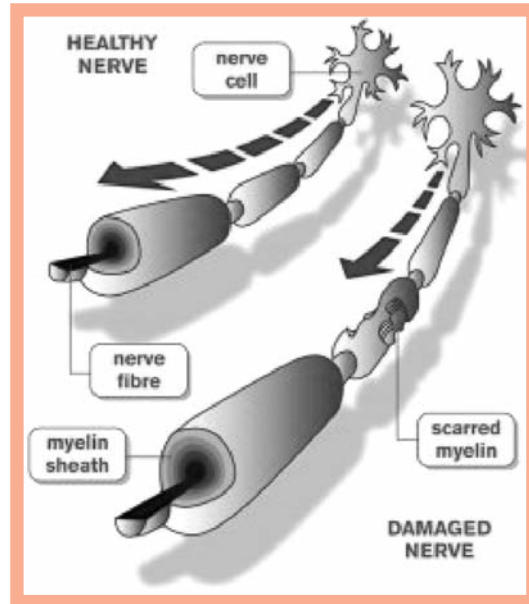
NEW MSRA RESEARCH

NEW MSRA RESEARCH TO DETERMINE IF SPECIFIC MUTATIONS INITIATE MS

Myelin is an insulating material that wraps around nerves to allow rapid conduction of signals from the brain out to other parts of the body. In MS, myelin in the central nervous system, i.e. in the brain and spinal cord, is damaged. Myelin proteolipid protein (PLP) is the most abundant protein component of central nervous system myelin and is essential for maintenance of the myelin.

The gene that makes PLP is located on the X chromosome, one of the sex chromosomes. Females have 2 copies of the X chromosome, whereas males only have a single copy. PLP is also very highly conserved, which means that PLP from many different types of animals is completely identical to the PLP found in people. When a protein is highly conserved, it generally indicates that the protein plays an essential role, and that the protein cannot tolerate having any changes or mutations made to it. This is supported by the finding that when males (who only have a single copy of PLP) have mutations in PLP, they develop a devastating neurological disease called Pelizaeus Merzbacher disease (PMD), in which myelin production is highly disrupted. In contrast, female relatives of PMD patients who have a mutation in one copy PLP generally do not show any symptoms, as they still have one good copy of PLP, which is sufficient to produce enough myelin to maintain nerve function. Fortunately, PMD is a very rare disease, and it has therefore been thought that PLP mutations only occur very rarely.

However, there have been two recent case reports in the scientific literature who met the criteria for MS but who had PLP mutations, although these mutations were different from those previously shown to cause PMD.



At the moment, it is unknown whether these PLP mutations might be related to the development of MS in these people, as very little is known about whether there are some non-dangerous PLP mutations that occur in healthy individuals. This is not thought to be the case, but no one has really looked.

One way to tell if the PLP mutations might be dangerous is to specifically generate these PLP mutations in otherwise healthy cells. If the cells then undergo a process called the “unfolded protein response”, this will be an indication that the PLP mutation might cause harm to the myelin producing cells in the brain and spinal cord and could potentially be the underlying cause for why some people develop MS. We will therefore generate the mutations identified in healthy cells of People with MS to see if the cells subsequently undergo the unfolded protein response. If they do, future studies would investigate more fully the potential role of PLP mutations in People with MS. Dr Judith Greer has been awarded \$24,526 for one year to investigate if specific mutations within PLP could potentially initiate MS.

Source: www.msra.org.au

EXERCISE BENEFICIAL TO PEOPLE WITH MS

10th August 2010

In a paper soon to be published in the journal *International Immunopharmacology*, researchers from the University of Tehran have added to the growing evidence base about the beneficial effects of exercise for people with MS. From a sample of 20 people with relapsing-remitting MS, 10 were randomly assigned to the exercise group and 10 to the control (no additional exercise) group. The exercise regime consisted of 8 weeks only of both aerobic and endurance training three times a week. Muscle strength and balance increased significantly in the exercise group, and the disability score decreased significantly. Blood markers of inflammation decreased markedly in the exercise group but not in controls.

The research shows the great value of a regular exercise program in MS, and strongly suggests that such a program not only improves current function and balance, but is likely to slow disease progression due to its effect on inflammation.

Source: www.overcomingmultiplesclerosis.org

BOOK REVIEW

MENTAL SHARPENING STONES:

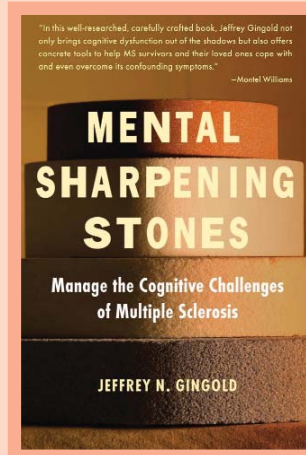
Manage the Cognitive Challenges of Multiple Sclerosis
By Jeffrey N. Gingold

Jeffrey Gingold is an internationally acclaimed author and person with multiple sclerosis. Here he builds on his prior volume *Facing the Cognitive Challenges of Multiple Sclerosis* with this book named *Mental Sharpening Stones: Manage the Cognitive Challenges of Multiple Sclerosis*. In this book he has assembled a collection of articles and interviews which feature techniques for dealing with cognitive issues and increasing and maintaining cognitive awareness.

He says in the introduction to this book, that "At the time of my diagnosis, I also didn't understand that this chronic disease would slow my thoughts and obscure recall. Even when I began to recognise that MS was interfering with my thoughts, I was unaware of any steps that I could take to preserve my cognitive connections"

Richard Cohen, Montel Williams, Colorado Chief Justice Mary Mullarkey and others speak openly about the steps they take to manage this common MS symptom. Through these interviews they offer practical suggestions to people with MS as well as insights and guidance for family members and friends.

Review by Rachael Turner-Ford



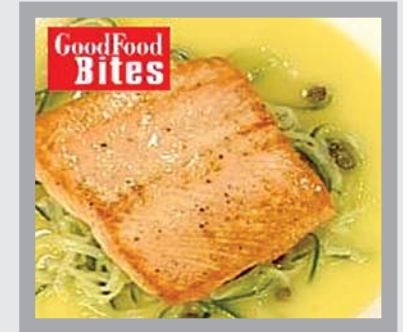
IMPORTANT MESSAGE FROM THE AMBULANCE SERVICE

We all carry our mobile phones with hundreds of names and numbers stored in it's memory. If we were to be involved in an accident or were taken ill, the people attending us would have our mobile phone but wouldn't know who to call. Hence this 'ICE' (In Case of Emergency) campaign.

All you need to do is store the number of an emergency contact person under the name **ICE (followed by their name)**. In an emergency situation, Emergency Services personnel and hospital staff would be able to quickly contact the right person by simply dialling the contact that has ICE before their name. Please pass this information on to all your friends and family members.

RECIPE CORNER

SEARED SALMON WITH BUTTERED CUCUMBER SPAGHETTI AND CAPERS



Ingredients

- 2 medium cucumbers
- 1 tbsp Olive oil (or olive oil spray if using a griddle pan for the Salmon)
- 4 Salmon, escalopes, thin
- 1 large pinch salt and fresh ground black pepper
- 1/2 tsp ground ginger(optional)
- 100ml dry vermouth
- 1 tbsp capers
- 75g Pure Dairy Free Spread
- 1 lemon, juice, freshly squeezed to taste

Method

1. Halve the cucumbers lengthways and scrape out the seeds. Finely shred the cucumber halves lengthways into long thin shreds, using a mandolin. Spread out the cucumber shreds on kitchen paper (to soak up excess moisture) and store in the refrigerator until needed.
2. Heat a large, heavy-based frying pan until hot. Add in the olive oil, heat through briefly and add in the salmon escalopes. If using griddle pan, spray first with olive oil.
3. Season the salmon with salt and freshly ground pepper and ground ginger, if using, and fry for 2-3 minutes.
4. Meanwhile, in a saucepan, heat up the vermouth. Add in the cucumber shreds and gently heat through the cucumber.
5. Add the capers and dairy free spread to the cucumber and shake the pan from side to side to help the mixture emulsify. Season to taste with salt and freshly ground pepper and lemon juice.
6. Divide the cucumber among 4 serving plates. Top each portion with a salmon escalope, turning the salmon over so that the fried side is upwards. Squeeze over a little lemon juice and serve at once.

Photograph and original recipe, courtesy of UK TV Food - Good Food Bites

The above recipe has been taken from the Multiple Sclerosis Resource Centre website – www.msrc.co.uk

MS GROUPS

For more information on these groups contact the MS Auckland Region Office on (09) 845 5921 or email info@msaki.org.nz

RODNEY

HIBISCUS COAST BUDDIES

3rd Tuesday of each month, 10.30am
At the Pohutakawa Room in the Whangaparaoa Library. All welcome.

UNDER 45s GROUP

Six weekly at each others homes.
If you have MS and are under 45 you are welcome to attend. Contact Allison at the office for more information.

NORTH SHORE

NORTH SHORE CAFÉ GROUP

1st Saturday of each month, 12.30pm
Kings Garden Café, Kings Plant Barn, Porana Rd, Glenfield. Contact Christine Ball (09) 444 6945 or 021 071 6752 after 4pm.

MAIRANGI BAY WATER-WALKING

Wednesdays 10.30am to 11.30am
At the Millennium Sports Institute with a Physiotherapist, Margo Angland. Contact the office for more information.

MAYFIELD COFFEE MORNING

1st Thursday of each month, 10.30am
At the Mayfield Centre, Glenfield. All are welcome.

AUT PHYSIOTHERAPY MS CLASS

Classes are held at AUT, Akoranga Campus, Northcote. Contact the clinic for details on (09) 921 9161.

CENTRAL

AQUA EXERCISE GROUP

Thursdays 10.30am to 11.30am
A hydrotherapy group is held at Epsom Girls' Grammar School Aquatic Centre. Contact the office for more information.

WAIHEKE GROUP

Meets several Sundays per year.
Contact the office for more information.

GREENLANE COFFEE GROUP

2nd Saturday of each month, 11.00am
Zinc Café, 205 Great South Road, Greenlane (by Autel Kitchen Appliances Showroom).

WEST

WEST AUCKLAND WATERWALKING

Fridays 11.00am to midday
West Wave Aquatic Centre, Henderson, with with a trained Physiotherapist.

WEST AUCKLAND YOGA

This class is currently on hold until further notice.

WEST AUCKLAND TAI CHI

There are some free 16 week Tai Chi classes available for residents of Waitakere City who have MS. Healthwest co-fund these programmes with ACC. They are held in a variety of locations during weekdays, so to register or find out more information you can contact them on (09) 816 8649 or e-mail info.taichi@xtra.co.nz

PT CHEVALIER SUPPORT GROUP

2nd Wednesday of every 2nd month,
from 10.30am to 12.30pm
Contact Judith Linton, Ph (09) 846 4783.

SOUTH

BEACHLANDS AQUA EXERCISE

Contact Margaret Strachan,
Ph (09) 536 6663.

PAPATOETOE HYDROTHERAPY GROUP

Wednesdays 11.00am to midday
At the Papatoetoe Pool, Sutton Cres.
Contact Gordon Baker, Ph (09) 275 5729.

PAPAKURA-TAKANINI SUPPORT GROUP

Last Tuesday of each month from 10.30am
Contact Lesley Shortland, Ph (09) 263 8132.

PUKEKOHE CAFÉ GROUP

1st Thursday of each month at 11.30am
Contact Sarah Toft, Ph (09) 232 2796.

BOTANY CAFÉ GROUP

3rd Thursday of each month
Whitcoulls Coffee Lounge, Botany Downs Town Centre. Contact Elaine Jones (09) 533 4160.

Our thanks goes to the following organisations for their support.



MS Groups are a great way for members to get together for friendship and support, whether it is simply for a chat or for some light exercise, make it your goal to go along to a group. All people with MS are welcome to attend any of the above groups in any area.

If you have an idea for a group or would like to start one contact the office on (09) 845 5921.

Opinions expressed in this newsletter are not necessarily those of the MS Society or the editors.