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2011 ART FOR MS
ACCESSIBLE ACCOMMODATION



**FAREWELL AND
GOOD LUCK TINA**

EDITORIAL

Hello Everyone,

Cooler days are at last here and whilst many of us have enjoyed the longer than usual summer it has been exhausting for many members.

We are now settled into the offices on the North Shore at the Mayfield Centre and whilst we have a lot less space than previously, down-sizing has had some very good benefits. Not least of which is the opportunity to streamline ourselves and 'clear our clutter'. It has taken some weeks to squeeze ourselves into our new rooms, but we are seeing the light at the end of the tunnel. From your point of view, very little has changed. **You still call us on the same number, email us on the same email addresses and fax us on the same numbers.** Obviously our postage address has changed (see *the front cover*), but we also have a re-direct on the old address for a few months just in case you forget.

Now that we are passed the distraction of relocation it is back to "business as usual" and there is plenty going on. At our **Annual AGM** on 16th April we said goodbye to committee members Roy Burgoyne and Gay Compton and welcomed David Compton, Ross Nordstrand and Madeline Robinson – you will find details of their background, along with that of Peter Wood our treasurer who joined us last year, in this newsletter (see *page 10*). The Committee also held a Special Meeting before the AGM at which it was unanimously resolved to sell the premises at Taylors Road.



Last week we had the sad task of saying **farewell to Tina French** who has moved on after thirteen years of service to the society. Tina's contribution over the years has been immeasurable and she will be sorely missed by many and certainly by me. I wish her every success in her new role (see *page 7*).

We have some great events coming up. Firstly on the 4th-10th July we have our re-vamped **ART FOR MS** event at the Aotea Centre in conjunction with the Auckland Studio of Potters. This will prove to be a very exciting partnership and I urge you to come along to our opening Auction night on Monday 4th July (see *page 4*).

You will notice that we have a member's event looming on Saturday 9th July in the form of a **Mid-Winter Lunch at the Lincoln Green Hotel**. This is a heavily subsidised event for members so represents great value for money (see *page 10*).

This year we are unable to run our **Annual Retreat** as Prof. Jelinek is unavailable, however, we are working on dates early in 2012 hopefully during the summer months. In the meantime we have a very special event planned in the form of a two-day, non-residential **retreat with Dr Craig Hased** for the weekend of August 20-21. We are very fortunate to secure Dr Hased for this weekend and places are limited so book early (see *page 6*).

Finally, with the move complete and our refreshed staff team and committee in place we are working hard to bring new energy to the society with new plans, new events and new funding. Please support us in any way that you can.

Cheers

Gary

SAVE THE DATE WE NEED YOUR HELP



As part of this year's MS Awareness Week will be holding our Annual Street Collection on Friday 2nd and Saturday 3rd September 2011.

We need as many volunteers out collecting as possible. Even if you can only **spare an hour or two of your time** it would help us to raise the profile of MS and raise vital funds. All the money raised will go towards our Field Worker Service, which provides a free service of experienced and qualified Field Workers to support people with MS in the Greater Auckland area.

If you are able to help with this years collection, please contact Reena on **(09) 845 5921** or email reena@msakl.org.nz.



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FUNDRAISING AND VOLUNTEER NEWS

HOST A DINNER PARTY RAISE MONEY FOR MS... AND WIN PRIZES

Dine @ Mate's Rates for MS and Win – a great new fundraising idea from the MS Society. Simply hold a dinner party for your friends... but make it tasty!

The value they place on your meal could win you a \$10,000 shopping spree at KITCHEN THINGS! The team who raises the most money for Multiple Sclerosis – WINS!

A team is comprised of two people who invite as many people as they wish to a dinner party at their home. As the hosts, you will buy the relevant ingredients and cook a 3-course meal comprising entrée, main and dessert. Guests bring their own alcohol. At the end of the evening the guests decide the value of each course and pay that amount to the hosts. The total amount paid is then donated to the MS Society of NZ.

The teams who raise the most WIN these fantastic prizes from KITCHEN THINGS!

First Prize (Top Fundraiser)	\$10,000 Shopping Spree
Second Prize	\$3,500 Shopping Spree
Third Prize	\$1,500 Shopping Spree

Ways you can maximise income from your dinner party:

- Hold two sittings
- Ask local suppliers to donate the ingredients
- Erect a marquee in your back yard
- Hold a neighbourhood dinner party
- Hold a themed dinner party eg: Indian, French or Moroccan!
- Arrange sponsorship from friends, family and work mates who cannot attend
- Encourage guests to get sponsorship from their friends, family and work mates.

Receive the recipe book for FREE!

A cook book will be compiled from courses cooked at the dinners. When sending in your money, hosts are encouraged to send in their recipes for inclusion in the cook book. All donated recipes will be acknowledged in the cook book and all teams will receive a free copy!

See the enclosed brochure for more information and entry form.



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

FUNDRAISING AND VOLUNTEER NEWS

ART FOR MS

We have some great news for you!!!! After postponing last years exhibition we are pleased to announce that ART FOR MS is back, re-vamped and bigger and better than ever.

Not only has it moved to an earlier slot in the year but we will be running it in conjunction with the Auckland Studio of Potters. This will give it a much larger variety of art both to view and to purchase and will raise the profile of the event. Also returning is our opening night auction and cocktail function where you can pick up some great bargains.

Book your place now and support this great event.



About Auckland Studio of Potters

The Auckland Studio Potters Society serves the pottery community. Whether you are a professional or an absolute beginner, they offer teaching, studio and firing facilities, support, friendship and fun. Here's just some of the services provided:

- A full range of pottery classes, from absolute beginners to a course run in co-operation with the Otago Polytechnic School of Art leading to a formal tertiary diploma.
- Specialist workshops led by visiting potters from New Zealand and overseas.
- A monthly newsletter.
- Regular social events for members.
- Our annual open day and fundraiser – the Big Clay Day Out.
- An annual members exhibition.
- and lots more.

To find out more phone about Auckland Studio Potters phone (09) 634 3622 or visit www.ceramics.co.nz

BIG NEWS! FUNDRAISING EVENT

The society is the beneficiary and a key part of a big and very exciting event coming up at the end of the year. It involves cycling and the Harbour Bridge and Busway. It will be a MAJOR Auckland event.

It is a big secret until the 17th June, but we are just 'tipping you the wink' as there will be some great ways in which you can be involved – watch this space and listen for media reports on the 17th June. And then get on your bike and join us!!



SUMMER COMPETITION WINNERS

Congratulations to the following people for winning our Summer Competition, they each got to choose a fabulous Peta Mathias item:

Tracey Hendrix

Anne-Marie Raleigh

Wendy Dancer

Jennifer Cassels

C K Smith

Beverley Kempthorne

FIELD WORKERS UPDATE

FROM DIANE - NORTH SHORE

We are finally getting organized after the move and "decluttering". I'm trying to gradually catch up with members especially those of you who are new to me. If you want to contact me I work Wednesday to Fridays and for those who are busy my email address is diane@msaki.org.nz



Field Workers recently attended a Consumers Forum put on by the Ministry of Health Disability Support Services to discuss their new model for funding and found it very interesting.

Over the years, consumers and service organizations such as ours have been complaining that the services provided to people with disabilities don't meet individual's needs and it now looks as though the MOH has been listening. For more information and how you can get a copy of these proposals see page 14.

Finally, our Millenium Pool Group now has a new Instructor and a new programme and we are looking for new participants to join this group

FROM DIANNE - SOUTH AUCKLAND

What a mixed few months we've had! The Christchurch earthquakes, the Japanese earthquake and tsunami, not to mention Tornados. How does the mind, body and soul deal with these major catastrophes?

My heart goes out to you Cantabrians who have had to deal with the aftermath of not one, but two major earthquakes in such a short period of time. And to other Kiwis who have lost loved ones as well. If any of you with MS have been relocated to the Auckland area, please don't hesitate to contact us here at the Auckland branch of the MS Society if you would like some support while you are here.



This also highlights to me that we must all have an emergency plan. Especially those of you who are incapacitated in any way. Please make sure that you not only have an emergency kit with enough food, medications etc. to survive for 3-4 days, but an escape plan organized as well. Speak to your families and caregivers to help come up with a plan so that you at least feel that you have some control over how to deal with an emergency such as we have experienced recently. For more information on being prepared, emergency kits and plans visit www.getthru.govt.nz

FROM GEORGA - WEST AUCKLAND

I have enjoyed meeting some of our lovely MS members who live in the Hibiscus Coast area, and will continue to meet and catch up with people in the North and West as the year progresses. Do contact me if you have any concerns regarding your MS. Also I love to receive catch up emails as they're a great way to keep in touch; my address is georga@msaki.org.nz I look forward to hearing from you.



I just wanted to mention some great resources to investigate.

1. Age Concern. Their website is www.ageconcern.org.nz or look up your local branch in your phone book if you don't have internet access.
2. Check out the website www.agewell.org.nz which is promoting healthy aging throughout New Zealand.
3. Your local Citizens Advice Bureau is also worth remembering when searching for information. Look up your local branch in your phone book, or their website is www.cab.org.nz

FROM GLEN - CENTRAL AUCKLAND

A few reminders. Just to clarify that any financial member can attend ANY or ALL of the pool groups and also most of the support and social groups.

Some members appear not to be aware that if they wish to receive the National MS Society quarterly magazine 'Voice' they now need to request this directly with National (in the past they were sent with our newsletters). The contact details are: **0800 675 463**, email: info@msnz.org.nz or visit the website www.msnz.org.nz Voice magazine is a fantastic full colour magazine which has a great deal of information and research available, as well as information on symptom management.



If a person uses the ambulance service several times a year it is well worthwhile paying the \$35 yearly sub to St.John Ambulance which can be claimed on the Disability Allowance for those who are eligible to receive it.

Remember while it is still fairly hot during the day try to leave any important decision making to a time of day when it is cooler, as the heat usually causes inflammation in the thinking process as well as the physical aspects of MS!

TWO-DAY RETREAT WITH DR CRAIG HASSED

The Essence of Managing MS – A two-day non-residential Retreat with Dr Craig Hased is being held in Central Auckland on the 20th & 21st August 2011.

All the great wisdom traditions put an emphasis on holistically-based self-care principles as being the core of any approach to healthcare. Unfortunately, this holistic approach has tended to be marginalised compared to the practitioner-focused illness model. It makes much more sense and produces far better outcomes when people living with chronic conditions such as MS are more actively engaged in their own healthcare. The work of Professor George Jelinek has been ground breaking in relation to taking this approach to MS.

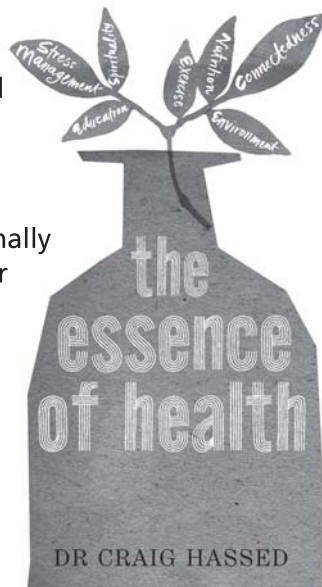
The Essence model can be used personally and professionally as a way of promoting wellbeing and also preventing or managing a wide range of physical and mental health problems. Essence is an acronym which stands for:

- E ducation
- S tress management
- S pirituality
- E xercise
- N utrition
- C onnectedness
- E nvironment

This program will be both experiential and informative. From an experiential perspective, mindfulness-based principles and practices will underpin the daily program with a focus on how these skills and practices can be used personally.

This, along with an exploration of mind-body medicine, constitutes the 'stress management' component of the Essence model. Cultivating awareness and mental and emotional wellbeing along with understanding a range of behaviour-change principles are central to being able to make and maintain other healthy lifestyle changes.

Each day's program will also include focus on each of the other Essence elements. For example, we will explore the sources and importance of spirituality or meaning in one's life; the benefits of physical activity and how to implement it safely; the importance of a healthy diet, food as medicine and healthy weight management principles; the importance of relationships and



social support; the importance of healthy environment, and not just the physical environment but also the emotional and urban environments.

Apart from providing up to date and evidence-based information about these elements and their impact upon health, there will also be an exploration of behaviour change strategies and goal setting to provide further insights and skills for how to apply these elements in one's daily life. Although the Jelinek program is not based upon the Essence model, all of the key elements of that program will be explored.

About Dr Craig Hased

Dr Craig Hased is Senior Lecturer at the Monash University Department of General Practice where he has authored and pioneered new topics into the undergraduate and post-graduate curricula. These include mindfulness-based stress management, meditation, holistic healthcare, mind-body medicine, psychoneuroimmunology, complementary therapies and self-care management. Extending his work as a General Practitioner, Craig's research and clinical interests focus on the management and treatment of chronic illnesses using mindfulness-based stress management.



To date, he has published over 65 articles in several Australian medical journals. Since 1999, he has been writing a regular column for the *Australian Family Physician* on the "Philosophy of Medicine", which was compiled into a book in 2000 called, "New Frontiers in Medicine". He has since gone on to publish Volume 2 of "New Frontiers in Medicine" and another book called, "Know Thyself" focusing on mindfulness-based stress management. Most recently he has published "The Essence of Health: The Seven Pillars of Wellbeing".

Craig is a regular group leader and presenter at The Gawler Foundation's Residential Wellness programs, and leads meditation retreats for public and health practitioners.

The Cost: (all inclusive for both days):

Member of MS Auckland Region:	\$200.00 per person
Others:	\$255.00 per person

To register: please contact Shelley on (09) 845 5921 or shelley@msakl.org.nz and make your booking.

Accommodation: Through our affiliation with Quest Hotels we have managed to secure discounted top-quality accommodation in Central Auckland. Please ask for further information at the time of booking.

FAREWELL & THANK YOU TINA

Long-serving staff member Tina French has resigned to take up a new position with the Mobility Dogs Trust.

Over the course of many years Tina has become a recognisable face of Multiple Sclerosis for newspaper and magazine readers. Bright and cheerful, she was frequently asked to appear in photographs to appear with articles on Multiple Sclerosis or Riding for the Disabled (RDA). She has also featured on TV and Radio.



Tina, who worked as a dental chair-side assistant in her previous career, joined the North Shore MS Society nearly two decades ago and became a committee member soon afterwards. On a voluntary basis, she shouldered an increasing amount of administrative work for the society as its membership grew over the years.

Eventually the society scratched up enough funds to pay her a very modest salary for that part-time work, which she continued until the North Shore society merged with Auckland in 2008. Although she was by now finding mobility an increasing problem, Tina accepted a job with the merged society, drafting applications for grants from charitable organisations and trusts. It was a demanding task, as money became tight and the number of organisations seeking help steadily increased, but she brought to it a high level of knowledge and skill which produced more successes than many others might have been able to achieve.

A few months ago Tina became the proud owner of Ezra, a mobility dog. A handsome two-year-old golden retriever. Ezra carries out an increasing range of useful tasks for his owner, like bringing the telephone to her, opening and closing doors, picking things up from the floor and pushing lift buttons.

On one recent occasion when Tina had a fall in the bathroom and was unable to get herself mobile again. Ezra got the phone, so that Tina could phone her friend to come and help her, and Ezra opened the door to let them in. Without Ezra's assistance, Tina could have been stranded, cold and wet, until her husband came home from work.

Tina is married to Roy Burgoyne, who retired this year from the MS Society committee but is continuing to help with organising the society's proposed art exhibition.

By Graham Wear

NUTRITION CONSULTANT

Sandra Perry is one of our members who was diagnosed with MS around 5 years ago and attended the Jelinek Retreat on the Coromandel in 2007. She has followed Jelinek principles ever since including the diet.



This sparked an interest in nutrition and particularly the role it can play in improving health outcomes and so she enrolled in the Wellpark College 2-year Diploma of Nutrition course. She has now qualified as a Clinical Nutritionist and has gone into private practice. She is also a member of the Clinical Nutrition Association and the NZ Nutrition Foundation.

Sandra's company, 360° Nutrition, is based in an office at Albany Fitness (gym) in the Tennis Centre, Oteha Valley Rd extension in Albany. There is wheelchair access as well as disability parking and her office is on the ground floor.

Sandra's 1st consult is for 1¼ hours and involves a full health history, diet and lifestyle assessment and client goals are discussed. The 2nd visit of ½ hour, normally several days later is a presentation of a wellness/nutritional plan and recipes which can be personalized to adapt favourites. The cost for the 2 consultations is \$120. Ongoing visits are \$40 for ½ hour.

Sandra works in a holistic manner and aims to demystify Jelinek's diet, making it simple and easy to follow. She is also very good at modifying recipes or developing them. She is also willing to advise people who want to eat healthily but not necessarily go all the way with Jelinek. She discusses how food works in the body, supplementation and has a range of practitioner only supplements.

For more information or to make an appointment please contact Sandra at 360° Nutrition, Phone **(09) 415 2676** or email nutrition360@xtra.co.nz

FIRE SAFETY

With the cold winter chills slowly clipping our heels and into our homes it is a timely reminder to check on all those heating appliances, we so often take for granted and yet too often cause us some pain, suffering and in some extreme instances, hardship. Now is the time to check your Electric Blankets, Smoke Alarms and that you have a good escape plan. For more information contact your local fire station or go to www.fire.org.nz or www.nsupport.co.nz/fire/

WORK & MULTIPLE SCLEROSIS

Experts describe strategies that help Multiple Sclerosis patients cope with symptoms of the disease.

How to handle workplace issues when you have Multiple Sclerosis.

Elissa Levy, a 37-year-old with secondary progressive Multiple Sclerosis (MS), is living proof of the unpredictability of this progressive neurological disease that affects the central nervous system.

Soon after being diagnosed in January 2002, her physical status plummeted quickly. The former fitness buff who regularly skied and jogged describes the overwhelming MS-induced fatigue that plagued her almost daily. *"Sometimes my eyes hurt too much to watch TV."* Levy tells WebMD.

During that period, she traded her running shoes for a cane, broke off a relationship with someone she had once considered marrying, and relinquished a long-sought full-time position as director of a new charter school, taking up part-time work instead.

Then, just as quickly as the symptoms struck, they abated. *"I had tried all the drugs on the market for MS. As a last resort, I even did chemotherapy."* She found relief through an experimental drug (not yet approved by the FDA for MS).

Now, for the second time in three years, she's had to evaluate her future. *"I still dream about going for a jog. But now I can walk home from a movie 20 blocks, instead of taking a cab."* Levy says. She is back to work full time, sometimes doing 12-hour days. And she's re-established a relationship with her old boyfriend.

Through the ups and downs of the disease, people with MS must go on with their lives. Very often, that means making long-range decisions about how to live, from employment to recreation – and being open to re-evaluating them as needed. In addition to these 'big picture' decisions, practicing seemingly small lifestyle strategies can make the disease more manageable.

Working With MS

Like many others with MS, Levy was forced to make decisions about her professional life. Among the questions she faced: Do I tell my employer and, if so, when? Can I continue working? What accommodations will I need?

New laws, ever-increasing resources, and improved attitudes are making these decisions easier. Currently, 43% of adults who have had MS for 12 years retain employment, according to an ongoing nationwide study sponsored by the National Multiple Sclerosis Society (NMSS).

But some experts believe that percentage could be higher. *"Employers may have preconceived ideas about what a person with disabilities can do. It takes time to change attitudinal barriers. There's still work to be done."* says Steve Nissen, director of employment programs at the NMSS.

That's why, for now, it's generally up to the employee with MS to initiate any discussions involving disclosure or accommodation requests in the workplace.

Nissen considers disclosure (the whens, whos, and hows of it) one of the most difficult aspects of working with MS, or any disability.

Before disclosing, Nissen suggests the following: *"Ask yourself: 'What's going on to make you think it's time to disclose? Are you having new or different symptoms that's posing a challenge at work? Are you having trouble meeting deadlines, or missing time?'"*

How to Tell Your Boss

Often, disclosure accompanies a request for special workplace accommodations. The approach can sway the outcome, Nissen notes. *"It's more than saying 'This is what I need from you.' It's 'Here's how I can be more productive, effective, and reliable.'"* Nissen tells WebMD.

In the best-case scenario, such discussions with an employer begin as open, two-way dialogues. *"It really needs to be an interactive process. You can't just go in there, make your demands, and walk out."* Nissen says.

"When it comes to accommodations, there are so many different possibilities based on symptoms and job duties." Nissen tells WebMD. An accommodation may mean an altered work schedule with shortened hours or telecommuting on an as-needed basis when fatigue becomes overwhelming. It may mean adaptive equipment that allows an employee to talk into a computer rather than tap on a keyboard. It might mean keeping one room at a lower temperature than the rest of the office, if heat sensitivity is an issue.

"These types of accommodations seem basic but they can really make a difference." Nissen says. Some cost more than others. To find out what's available, Nissen recommends that employees start researching locally, beginning with an area NMSS chapter and incorporating other resources such as one's state office of vocational rehabilitation.

Alternatives to Work

Choosing not to work full time anymore doesn't have to mean an end to productivity. *"There are still ways to contribute as an active member of*

society." Nissen notes. Levy serves as a prime example. Having cut back to part-time work while battling daily pain and fatigue, she continued to find meaning through volunteer work.

"I stayed positive." says Levy who, almost immediately after being diagnosed, got involved in fundraising for the disease. *"That's where I found my support group – among other fundraisers."* Levy tells WebMD.

Attitude Matters

Clearly, how people with MS cope makes a difference in their day-to-day existence. *"Those who have the hardest time are those who see it as a war to win. That's a setup for feelings of failure, guilt, and inadequacy when and if they can't beat it."* says clinical psychologist Rosalind Kalb, PhD, director of the NMMS Professional Resource Center.

"Those most successful are those who say 'I can't win the war, but let's look at which aspects I can conquer.'" Kalb tells WebMD. To this end, Kalb urges patients to break the disease down into individual challenges, whether fatigue or spasticity. *"This way, they feel like they're managing the disease rather than vice versa."* she says. Lifestyle choices can also make an impact on one's ability to manage MS.

Impact of Exercise

Exercise is one such choice. *"Many years ago they used to say 'Don't exercise, it will make you too tired.' Now, we're encouraging patients to stay as active as possible."* says Sheila Schaffer, a physical therapist at Kernan Orthopaedics and Rehabilitation Hospital in Baltimore.

New research results promote physical activity. One study found that exercise improved fitness and function in people with mild MS and helped maintain function for those with moderate or severe MS. Investigators found aerobic exercise that incorporated balance training to be the most effective type. In yet another study, an eight-week progressive resistance-training program improved walking and overall functional ability in people with moderate MS.

Diet

Researchers have begun to evaluate the role of diet and certain antioxidants in relation to MS. *"There's a need for a well-balanced diet. I also recommend that patients take a multivitamin."* says Walter Royal III, MD, associate professor of neurology at the University of Maryland School of Medicine. Other experts stress the importance of a fiber-rich diet.

Royal and other researchers are exploring the potential role of vitamins D and

A in the clinical course of the disease. For now, he does not recommend specific supplementation. *"It can be quite hazardous to take excessive amounts of either vitamin."* Royal tells WebMD.

Alleviating Stress

For anyone with MS who needs a good reason to relax, here's one. Studies have linked stress to worsening MS symptoms. In one study, investigators recorded subjects' stressful life events unrelated to MS, like financial problems or death of a loved one. Stress caused by these events doubled the risk of an MS exacerbation.

Relaxation techniques have worked for Levy. Besides taking her medicine regularly, Levy claims that meditation has made the biggest difference in her life. *"My meditation helps the most. It keeps me focused on the present and allows me to stay centered."* Levy tells WebMD.

"That said, you can't stop thinking about the future altogether." she adds.

By Elizabeth Heubeck

Source: www.webmd.com, March 2011

FIAT WHEELCHAIR ACCESS MPV

Available for the first time in New Zealand from Drive NZ Classic Ltd, a range of Fiat Doblo right hand drive compact Disability Access Vehicles from Europe that are economical, powerful, fun to drive, and priced within your budget.

With a choice of new or used, Hi Roof or Low floor, all with 5 passenger seats plus excellent luggage space, and easy rear ramp access to a mid-mounted wheelchair station with ample headroom to accommodate all chairs, including powered Chairs and Scooters, plus 1 or 2 regular passenger seats alongside, and 2 front seats.

They are located at 167 Kitchener Road, Waiuku. If you would like some more information on these vehicles please contact Roger Phillips on **021 512 568**, or email roger@drivenzclassic.com

You can also visit their website www.drivenzclassic.com/fiat



Fiat Doblo Low Floor with rear ramp

COMMITTEE PROFILES

We have been fortunate to attract many fine and talented people to serve on our Committee over the years and this AGM was no exception. Even though we had to say goodbye and thank you to both Gay Compton and Roy Burgoyne we welcomed new members of the committee. Thank you to Madeline Robinson (Secretary), Ross Nordstrand and David Compton for stepping up to the roles and also to Peter Wood who joined us as Treasurer last year.

We must also acknowledge the sterling work of Bruce Cameron our long-standing Hon. Secretary who has been a Committee member for over ten years and our Secretary for eight of those years. This year, Bruce has decided to step down from the Secretary's role (whilst remaining on the Committee) and hand over the reins to Madeline Robinson. The Committee offer their grateful thanks to Bruce for his considerable efforts over the years.

PETER WOOD

Peter originates from Wellington where he attended Wellington College. This was followed by a Bachelor of Commerce from Victoria University. His career as a Chartered Accountant commenced in 1961. Peter, with his wife Maureen and their four children, moved to Tauranga to join the accounting firm of Sinclair Wood, now Wood Walton Chartered Accountants, as a Partner in 1986.



As well as being a Senior Partner of Wood Walton, Peter is a Justice of the Peace and a Director of numerous companies and other organisations. He is a respected and trusted advisor to many local business people and a Trustee of the Bay of Plenty Education Trust.

ROSS NORDSTRAND

Ross originally qualified as a Cabinet Maker, going on to build motor homes, before being diagnosed with MS at the age of 25. Ross unfortunately had to give up his passion due to it being such a practical, manual career, and went on to develop a love of all things IT.



Ross was one of the founding members of the Activity Group with the North Shore MS Society along with standing on the Committee in the late 90's. He is appreciative of all the help and support the MS Society has given over the last 17 years and is excited to be once again making a contribution to the Society and the Committee.

MADELINE ROBINSON

Madeline's association with the Auckland MS Society started ten years ago when she was diagnosed with MS. During these ten years she has much appreciated the friendships formed and the services offered to her through the society. She especially values learning and adopting George Jelinek's suggestions for living with MS, which she discovered through the Society shortly after her diagnosis.



Originally, Madeline's chosen career was as a teacher. After having three children she made the decision to change careers completely and began in Real Estate. Throughout the last 20 years Madeline has been involved in many facets of the real estate industry – selling, training, coaching, managing and business ownership. Currently, she contracts as an assessor of candidates completing the National Real Estate Courses.

Madeline is now delighted at this point in time to be in a position to contribute to the Society in the role as Secretary.

DAVID COMPTON

David is Director/Franchisee of Quest Newmarket in Auckland. He has previously worked in Corporate Communications, Television and Radio.

David is married to Gay, a previous committee member and a person living with MS.



COME ALONG TO THE ANNUAL MID-WINTER LUNCH

This has been booked for the 9th of July at the Lincoln Green Hotel 159 Lincoln Road, Henderson, Waitakere.

Discounted tickets are only \$20.00 per person and can be bought in advance by contacting Shelley on (09) 845 5921 or email shelley@msakl.org.nz



SUNLIGHT MAY REDUCE THE SEVERITY OF MS

New research into the neurodegenerative disease, Multiple Sclerosis (MS) offers insight into the link between sunlight, vitamin D3, and MS risk and severity. The research, published in the *European Journal of Immunology*, studies the relationship between the sunlight-dependent vitamin D3 hormone, immune cells, and the risk and severity of autoimmunity in an experimental model.

Expensive first-line treatments for MS modestly reduce the frequency of autoimmune attacks but do not slow disease progression, when the patient's immune system operates against the body's own tissues. More expensive second-line treatments slow disease progression but carry high risks.

The origin of MS attacks remains unknown. However, new research indicates that a patient's vitamin D3 supply (derived mainly from sunlight exposure) is strongly related to disease activity; the fewest attacks and slowest progression occurred in patients with the highest vitamin D3 supplies. This research suggests that increasing vitamin D3 supplies might be a safe, effective and inexpensive therapy for MS.

"MS is a genetically and immunologically complex disease." said lead author Dr. Colleen Hayes from the University of Wisconsin-Madison. *"It is currently incurable, but environmental factors, such as vitamin D3, may hold the key to preventing MS and reducing the impact of the disease in MS patients."*

Dr Hayes' team originally suggested that the sunlight dependent hormone D3 (1,25-dihydroxyvitamin D3) may restrain the autoimmune attacks that cause MS based on the strong negative correlation between sunlight exposure and MS prevalence, the need for UV light to catalyze vitamin D3 formation, and the presence of receptors for the vitamin D3 hormone in T lymphocytes. They proposed that the vitamin D3 hormone might act on these receptors to control the T lymphocytes responsible for autoimmunity.

"Our new study investigated the protective effects of the vitamin D3 hormone in an experimental model of MS when the hormone receptor was either present or absent in T lymphocytes. We found that the hormone's protective effects were only evident when these receptors were present in autoimmune T lymphocytes. Our new data suggest that an action of the vitamin D3 hormone directly on pathogenic T cells leads to elimination of these cells." said Hayes.

Actions of the vitamin D3 hormone on other immune cells have not been ruled out, but such actions were not sufficient for protection from autoimmunity if the hormone could not act on the pathogenic T cells.

"This information is important because it provides a plausible biological explanation for the negative correlation between UV light exposure and MS disease risk and severity." concluded Hayes. *"My research group and others around the world are building the scientific knowledge base needed to devise vitamin D-based strategies to prevent and treat MS"* she adds. *"There are many uncertainties and unanswered questions. However, understanding how sunlight and vitamin D3 may be working at the molecular level contributes greatly to our knowledge base and brings us closer to the goal of preventing this debilitating disease."*

Source: *Science Daily* March 2011

MARATHON EFFORT

At the beginning of the year Megan Burns rung her mother Margaret (who has MS) asking how she could make some money while doing the Rotorua Half Marathon. Megan, who previously won a scholarship through the MS Society to go to Outward Bound felt she wanted to give something back as a thank you.

Margaret suggested that she set up a fundraising page on the internet which she did, her effort raised \$100 for the society. Margaret says "she wouldn't have done it if it wasn't for the opportunity she was given by the MS Society to attend Outward Bound. I think they find and believe in their inner strength!"

Outward Bound runs a wide variety of courses for all age groups and abilities for more information visit www.outwardbound.co.nz

For information about fundraising online visit www.fundraiseonline.co.nz

If you or someone you know has done or is planning to do something to raise money for the MS Society we'd love to hear about it and to let others know email editor@msaki.org.nz



ACCESSIBLE ACCOMMODATION

The accommodation industry need to display degree of accessibility on their own website. Alexia Pickering is just the person to show them how.

Alexia believes that only then will travelers with disability know where to look for reliable information. It is called inclusion.

While she accepts that access information held on separate websites is valuable she believes that the accommodation provider should have information about the accessibility of the facility on their own website. She has developed a system where this can happen.

Because there was nothing about access Alexia personally visited and assessed over 500 establishments and published the guide book **'Accessible NZ'** – 5,000 copies were distributed by Tourism NZ to their outposts. There are no immediate plans to update, because these publications are just for *'the disabled traveler'* and the information is not the responsibility of the accommodation provider but the author.

The book was the result of a feasibility study where 157 individuals with different disabilities described what accessibility information they expected to know about an accommodation facility that they wished to stay in. Alexia used this as a guide to the questionnaire she has developed for the accommodation industry along with her own personal experience as a disabled person.

The questionnaire is not an audit for compliance with the Building Code, but seeks information that is important to a disabled traveler. For example, is the room spacious and does it have sufficient space of at least 800mm on both sides of the bed – we have all experienced access units having insufficient space beside the bed to transfer. How some providers expect a disabled person to get onto a bed from the end, and then crawl to the top is a mystery.

There are more seriously disabled people travelling with a portable hoist. Generally there is insufficient space under the bed to accommodate one. Alexia's questionnaire will seek this information. Further questions are – If a toilet commode is required, is one available? Is there a grassed area nearby for a guide or mobility dog? These are only some of the questions sought.

The responses are summarized into an appraisal and returned to the owner for inclusion on their website. The format has icons beside each comment.

Alexia cannot undertake this huge task on her own. She wants to build up a team of disabled people around New Zealand who can take a questionnaire

and complete it on different accommodation option e.g. hotels, motels, backpackers, bed & breakfasts etc. Training will be offered. You don't have to be an accredited BFA because you won't be doing audits for compliance, only completing a questionnaire.

The only catch is there is no money in it. Alexia is offering the accommodation industry this appraisal service for free. Alexia knows this industry and understands that accessibility is low in the pecking order when it comes to spending money on promotional material.

Why not join Alexia in helping to make this happen. You would only need to give a couple of hours of your time by visiting a facility, completing a questionnaire and then return it to Alexia. It could be your way of contributing to a worthwhile project that will benefit the lives of travelers with disabilities. If you have had the experience of arriving at a venue to find that it was not as accessible as they proclaimed, you will understand the frustration and hassle of finding an alternative.

If you'd like to help please email Alexia at alexiapickering@clear.net.nz

Alexia also has a very informative website called *Accessible Options NZ*, visit www.accessibleoptionsnz.com

Source: Without Limits December 2010

DRUG COMPANY ADVERTISING

The journal Emergency Medicine Australasia stops all drug company advertising

Emergency Medicine Australasia has become one of the first medical journals in the world to ban all pharmaceutical company advertising in the journal.

The editors, Professors George Jelinek and Anthony Brown, noted that information from the drug companies was often not objective or evidence-based, and while doctors generally deny they are influenced by such information, the evidence shows that it changes their prescribing habits.

Journal editors had long been critical of drug company advertising and the role medical journals play in the dissemination of this information. Choosing to forego the income derived from publishing such advertisements, the journal editors said they needed to draw a line in the sand and make a stand, in the hope that other medical journals would follow suit.

Source: www.overcomingmultiplesclerosis.org, February 2011

INTESTINAL PARASITE REDUCES ACTIVITY IN MS

Intestinal parasite administration is anti-inflammatory and reduces disease activity in MS

It has recently been argued that the hygiene hypothesis may explain part of the pattern of MS incidence around the world. MS is a disease of affluent countries where sanitation has effectively eliminated many of the organisms that previously inhabited the human gastrointestinal tract. Previous data suggested that MS is less active in individuals with some of these infestations, in particular, worm infestations of the bowel.

The researchers in this study from Wisconsin conducted a small pilot study of five people with MS to whom they gave an oral suspension of porcine whipworm, a non-toxic parasite that doesn't infect humans and is not contagious, but does provoke an immune reaction. They showed that this administration provoked a strongly anti-inflammatory reaction, reducing the number of new MS lesions from 6.8 on average before administration to 2 after administration, with a return to previous disease activity once the administration was stopped.

This is very exciting news! It paves the way for large scale trials of the whipworm administration. Who would have thought that one of the keys to controlling this illness might be in the very bugs we have been trying to get rid of?

Source: www.overcomingmultiplesclerosis.org (Prof Jelinek website)

SNIPPETS AND WEBSITES

SENIORLINE is a great website which contains a great deal of information to help older people navigate their way around the health system. It contains information on support for carers, resthomes, retirement villages and private hospitals. There is also some information regarding enduring powers of attorney and the gifting process. For more information visit www.adhb.govt.nz/seniorline

FREE

One of our members has just purchased a new printer. He is offering a 4-5 year old Lexmark 3470 printer free to anyone who is interested. It works well. Contact Diane at the office on (09) 845 5921 if you are interested.

MYELIN REPAIR RESEARCH

MS Society (UK) funds second stage of myelin repair research.

In December, we announced great news that scientists at the University of Cambridge had found a way of reversing damage to myelin using stem cells. The work was funded by the MS Society.

Today we're delighted to announce we've committed more than £2 million over the next five years to fund the second stage of this research.

Professor Robin Franklin and his team at the MS Society Cambridge Centre for Myelin Repair will work collaboratively with world leading experts in MS (like those based at the MS Society Edinburgh Centre for Translational Research and the MRI unit at the Institute of Neurology) to carry out the next stage.

In the first stage of the study researchers found a drug that could potentially repair myelin; in stage two they will:

1. Build on recent advances in myelin repair research, so it's possible to identify more potential MS treatments in the future
2. Do pre-clinical research to translate their laboratory findings into a clinical trial for people with MS
3. Eventually run a small-scale clinical trial to test the safety of this treatment in a small number of people with MS

This next stage of the work at the Cambridge Centre for Myelin Repair will start in April 2011 and finish in 2016. If the work proves successful, clinical trials in larger numbers of people will take place to reveal whether the potential treatment is safe and effective for people to use. Then it will need to go through the necessary regulatory hurdles before it's licensed and available. We're still 10-15 years away from a treatment coming through, but these are positive steps.

Simon Gillespie, Chief Executive of the MS Society, said: *"We've been consistently impressed with the world class work of the Cambridge Centre for Myelin Repair and we're delighted that the generosity of our supporters enables us to continue funding this outstanding research centre."*

Source: www.mssociety.org.uk, February 2011

VITAMIN D AND MS – TIME FOR EVIDENCE

Searching the internet for “Vitamin D and MS” will reveal over a million hits.

Many people believe that Vitamin D supplements can reduce the activity of MS, and different websites recommend that MS patients use Vitamin D supplementation. Vitamin D is naturally made in sun-exposed skin, especially in summer, but our increasingly indoor lifestyle and public health campaigns to reduce skin cancer have meant that less of our skin is exposed to the sun, and low Vitamin D levels are common, even in this sun drenched country.

As Vitamin D is readily available in 1000IU capsules, and is generally safe (with few exceptions), many people with MS take it. It also helps the New Zealand economy as the most common product is made from sheep fat.

However, we don't actually know whether taking Vitamin D supplements reduces MS relapses and brain inflammation, and we certainly don't know if the very large doses recommended by some authorities (up to 10,000 IU/day) are in fact any better than lower doses.

In order to address this huge need for evidence, Multiple Sclerosis Research Australia (MSRA) has convened a committee, 'PrevANZ', to explore funding and to run a trial of Vitamin D supplementation. It involves providing different doses to people with the earliest signs of relapsing-remitting MS, ie people who have just suffered their first MS-like attack.

The PrevANZ committee are also exploring international collaborations. As a delegate of this committee, Dr Helmet Butzkueven said *“I was invited to present to a Scottish summit on Vitamin D in MS, held in September 2010. Pleasingly, I discovered that a similar trial is planned in the UK and is also awaiting funding decisions. We agreed in principle to share protocols and information, and sincerely hope both projects will be funded.”*

The Scottish summit on Vitamin D in MS was brought about by Ryan McLaughlin, aged 15, from Glasgow. Ryan's mother has MS and he has highlighted the urgent need for improving Vitamin D supplementation in Scotland, given the extremely low levels in Scottish people. For more information visit www.shineonscotland.org.uk

The next step is to finalise the resources needed for a comprehensive study. MSRA and PrevANZ hope that this will allow us to generate the evidence required to prove Vitamin D is a relevant treatment and preventive measure for MS.

Source: MSRA Next

MOH NEW MODEL FOR FUNDING

A new model for supporting disabled people: Disabled people want a good quality of life and more choice and control over the support they receive.

The Ministry of Health (MOH) discussed the work they had been doing to streamline services at recent Consumer Forums held throughout the country.

They talked about:

- The new model for supporting people with a disability
- Individualized funding for consumers
- Supported living options
- Ideas for new respite support models
- Carer Support
- Community living options
- Child and youth projects

We had the chance to discuss these topics after the MOH presentation and raise any ideas or questions that we had. Overall we found the Forum very interesting and helpful.

For more information on these projects and the Disability Support Services Draft Strategic Plan 2010 to 2014 and to obtain the Booklet *'Your Guide to Disability Support Services'* go to the Ministry of Health website www.moh.govt.nz/disability or free phone **0800 DSD MOH (0800 373 664)**

By Diane Hampton

MORE SNIPPETS AND WEBSITES

CHIEFLY CHAIRS are a company who design and sell chairs in New Zealand. They specialise in providing chairs in the orthopaedic and health related fields. They have been providing tailor made chairs for the past 10 years Their designs can fit a variety of customer needs including size, infirmity or disability. For more information on products available please visit www.chair.co.nz. You can also call toll free on **0800 0212 4247**, or email info@chair.co.nz for a current product list.

CUSTOM GRIP design and provide a large range of custom fit gloves for the wheelchair user. All gloves are designed by a wheelchair user. To view the current range of gloves available visit www.custom-grip.com. You can also ring **(09) 278 4885** or email customgrip.cooper455@gmail.com for a current product list.

BOOK REVIEW

A MEASURE OF TIME - MY LIFE WITH MS

By Lauren Singer

Whether you have recently been diagnosed or you have had MS for some time, this easy to read book is a must. Lauren Singer is a remarkable South African lady who will inspire and astound you with her sincerity and tenacity. She almost makes having MS sound easy! She takes a no nonsense approach that will appeal to you. And she even throws in a few chuckles to boot!

Lauren has been living with MS for more than 23 years, but was only formally diagnosed after 12 years. Of her diagnosis she says: *"I felt I had emigrated to another country. The signposts had all changed and the language was different."* So after diagnosis what did she do? Simply learn about the illness. As much as she could. And this knowledge she now brings over in her own striking matter-of-fact manner that makes this book a definite must have on any bookshelf. And, it is equally suitable for family and care givers as well.

The author provides useful references, contact numbers and web site addresses at the end of her book.

This is a book you will refer to frequently! For inspiration, for reassurance, this is the book that you will return to on your "just tell me about it" days!

Review by Jacob Bish

Read more about Lauren and her books at www.laurensinger.co.za



Lauren Singer with Professor Fred Huggins, DHH (Fred) and Rt Hon Capt Paddington Pepper, DHH (Pepper) her loyal service dogs.

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.

RECIPE CORNER

FISH CAKES

Ingredients

- 2 large tins tuna in spring water drained
- 1 small onion
- 2 tbsp chopped coriander
- 3-4 small potatoes
- 2 egg whites
- 1 tbsp fish sauce
- a bowl each of flour, egg white and breadcrumbs

Method

1. Cook potatoes then mash.
2. Fry onion lightly in smidge of olive oil.
3. Add all other ingredients, shape into patties.
4. Then roll in flour, then egg white, then crumbs.
5. Cook in non stick pan with small amount olive oil.
6. Serve immediately with a lime wedge and your favourite dipping sauce

The above recipes have been taken from www.overcomingmultiplesclerosis.org



Retirement Living at its Very Best!

Offering the very best of Independent and Assisted Living,
Resthome and Hospital Care.



Join us for lunch!

We invite you and a friend to join us for a complimentary lunch any day, Monday to Friday.



Please contact Brooke Read
on 575 1563 and book the day
prior to arriving.
184 St Heliers Bay Road, St Heliers


A Ryman Village

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 Pohutukawa 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 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 Institute of Sport. Contact the office for more information.

MAYFIELD COFFEE MORNING

1st Thursday of each month, 10.30am
Held at the Mayfield Centre, Glenfield.

AUT PHYSIOTHERAPY MS CLASS

Held at AUT, Akoranga Campus, Northcote. Contact the clinic for details (09) 921 9161.

CENTRAL

AQUA EXERCISE GROUP

Thursdays 10.30am to 11.30am
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).

PT CHEVALIER SUPPORT GROUP

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

WEST

WEST AUCKLAND WATER WALKING

Fridays 11.00am to 12.00pm
Held at West Wave Aquatic Centre, Henderson.

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 (09) 536 6663.

BEACHLANDS SUPPORT GROUP

Meets Six weekly at different venues.
Contact Linda Reid on (09) 536 6215.

PAPATOETOE WATER WALKING GROUP

Wednesdays 11.00am to 12.00pm
Held 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.