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IN THIS ISSUE:

SUPPORTERS THANK YOU LUNCH

MS INFORMATION DAY REVIEW

BE A BUCKETEER

MY STORY - MY AMAZING BROTHER

DR WILLOUGHBY'S LECTURE AT THE INFORMATION DAY

EDITORIAL

May has been such a busy month with a number of events running and other activities that have stretched us.

The Information Day was extremely well run with great content from a diverse range of people. The keynote presentation from Dr Ernie Willoughby, our Patron was superb and very well received.



We ran a Cheese and Wine evening for potential Street Appeal collectors and although turnout was lower than expected we had a good evening nonetheless.

With Winter now well and truly upon us there is a tendency to want to go into hibernation but now is a great time to get moving, get out there and do something new. Why not join in some of the great activities and groups that are on offer (see back cover).

One of the key focus areas this month is to complete our subscription drive – a second letter has gone out to all those members that have not renewed their membership and paid their subscriptions for 2010. This money is really important to us and we would be very grateful if you could return your subs in a timely fashion. Obviously every mail out that we have to do costs the society money that could be spent on client services.

We only get a very small amount of money from Government (less than 8% of our annual operating costs) and so every penny counts. Please help us to help you.

Gary

JUST A REMINDER...

We would love to hear from you! Letters to the editor, news, photos or anything you think may be of interest are welcomed. We can't promise everything will be able to get published, but your input would be appreciated. We wish to create an even better link between Around & About and its readership. 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 anju@msakl.org.nz and we will update your contact details.

SUPPORTERS THANK YOU LUNCH

At the beginning of May we were delighted to host a number of our key sponsors, supporters and representatives from grant and trust bodies to our annual thank you function.

Not only is this lunch a fantastic way for us to thank people for the exceptional contribution they make, over and above the norm, but it is also a great way for us to remind people about the work we do and the impact their support has.

We were able to show guests the Open Door documentary that was filmed and recently screened on TV3 – a very powerful testament to the impact MS can have on people's lives.

Feedback has been fantastic and will certainly have brought MS Auckland Region to the forefront of people's minds, which can only be beneficial for us.

Our thanks to Southern Cross Building Society for sponsoring the event, to the Langham Hotel for hosting us and to our wonderful new Ambassador Peta Mathias for joining us.



Amanda Billing who plays Dr Sarah Potts in Shortland Street (whose character has MS) with supporters Lorna and Clive Boyle.



FUNDRAISING AND VOLUNTEER NEWS

SUPPORTER PROFILE - THE WAREHOUSE, CLENDON

MS Auckland Region has been incredibly fortunate to receive the ongoing support from the team and customers at The Warehouse in Clendon.

In April 2009 The Warehouse introduced its policy of charging customers 10c to purchase a carrier bag (with the 10c to go to a chosen charity). The Warehouse Clendon nominated MS Auckland Region to be the recipient of the funds raised from the sale of plastic bags in their store.

Since then we have received \$3,141.62 from the store, which is a huge amount. This kind of ongoing financial support is greatly appreciated and incredibly important to us and of course, those we support. This amount is equivalent to funding the cost of a Field Worker out on the road for over a month. This in turn has a huge impact on the people we support and of course our Field Workers are our greatest asset.

To acknowledge their ongoing support we recently presented the Store Manager, Chris Carpenter with a certificate of appreciation on behalf of MS Auckland Region. Chris said, "It is a pleasure for us to donate to MS Auckland Region. We want to support an organisation that is active in our area which of course they are, having a Field Worker dedicated to supporting people in South Auckland. It is also good to work with a smaller organisation where we know our contribution makes a big difference to the people they work hard to support."

We would like to thank Chris and his team at the store, not to mention all their customers.



Chris Carpenter and Gary McMahon

ANZ STAFF FOUNDATION SPONSOR INFORMATION DAY

We were recently delighted to receive a cheque from the ANZ Staff Foundation presented by General Manager of Specialist Distribution, Craig Moffat. The grant of \$3,950 was awarded by the Foundation to cover the costs of running our recent MS Information Day. Without the grant we would not have been able to proceed with this event so we are incredibly grateful for their contribution.

The ANZ Staff Foundation has supported the work of the Society for many years with a number of grants that together have totalled \$13,850. The Foundation is funded by regular contributions made from ANZ staff, which are then matched dollar for dollar by ANZ. Their ongoing financial support enables us to proceed with numerous one off projects for the benefit of our clients. Therefore we would like to thank Craig for coming out to present the recent cheque and to the Foundation as a whole for their continued support.



FOOTLOOSE FUNWALK

Planned for November, this year's Footloose as promised will be revamped! Exact details are still to be confirmed, but we are looking at the second weekend in November and it will be in a much more public place – hopefully increasing the participant and fundraising potential but also helping us raise vital awareness amongst the public.

We are hoping to have 2 options this year with a walk and a run – so now would be a good time to start training.

This event has the potential to be a great fundraiser for the Society – the more people who participate, the more money we can raise. So watch this space and get ready to spread the word!

For more information on these articles contact Nicola at MS Auckland Region Office on (09) 845 5921 or email nicola@msaki.org.nz

FUNDRAISING AND VOLUNTEER NEWS

MS INFORMATION DAY 2010

Held on Saturday 15 May, 2010 at The Institute of Chartered Accountants.

The first part of the day consisted of two lectures.

The first was from Dr Ernest Willoughby, Patron to MS Auckland Region, Medical Advisor to the MS Society of NZ, and a member of the Advisory Board of the International Federation of Multiple Sclerosis Societies.

Dr Willoughby talked about the new medications that are being trialled and their possible side effects, the CCSVI that has hit headlines around the world and Stem Cell Therapy. Dr Willoughby felt that the CCSVI is not going to prove to be the cure that we all want. It was a very interesting and thought provoking talk!

The second lecture was given by **Nicola Kayes**. Nicola is a Senior Research Officer at AUT. Nicola covered information gained from MS Clients and caregivers. This research was aimed at government level for future possible changes to the way we cope and care for people with MS. Nicola emphasised the fact that they are happy to look at any ideas for future research and has asked if you have any to please get in touch with her. MS Auckland Region has already sent in an idea for researching people with MS and their employment.

The second part of the day consisted of a series of optional workshops ranging from lectures to workouts using thera bands, and even a sing song. The only trouble was making a choice as to which one you would go to!

Gwen Giles, continence Nurse Specialist who works in the community talked about the impact continence has on people with MS and their families, and the appropriate treatment provided empowering people to cope better with their lives. Gwen's talk was not only informative, but entertaining as well. Just to lighten the mood Gwen concluded her talk by singing a song on continence while playing her ukulele.

Stewart Harvey, Auckland Branch Manager for The Public Trust gave an all important talk on how to help New Zealanders protect things in life such as family and property by arranging wills and Power of Attorney.

Liz Binns, a Senior Research Officer and Lecturer at AUT who is currently working on Neurological Rehabilitation Research gave her very enthusiastic and encouraging talk on Tai Chi and its benefits to people with MS.

Kate Perry, a Clinical Physiologist, currently working at The Community Neurobehavioural Service (CNS) in Pt Chevalier gave a very good talk on their service and how to access it. If you are having trouble coming to terms with your MS diagnosis and feel that you could use some help in this area, then please talk to your GP, MS Fieldworker, or MS Nurse for a referral to this service. This is a free service. Kate also gave some handouts which your Field Worker can send to you if you would like one.

Jenny Stewart is a Senior lecturer in Physiotherapy at the AUT. Jenny specialises in Neurological physiotherapy. Jenny gave us an enthusiastic talk on MS and keeping us physically mobile. She had us working out using a thera band. Good fun was had by all. Jenny may be setting up a one off session some time in the future. Watch this space.

Karen Forrester is an executive member of the NZ Carers Alliance and is also on the Steering group of the Complex Carers Group. Karen gave us an informative talk on carer support and how it relates to people with MS.

MS Auckland Region wants to sincerely thank the above people for their time, interest, and care to make this day one that we could learn from in a non threatening and fun environment. Thank you also to the ANZ Staff Foundation for the funding to run this day.

If you, our members, have things that you would like addressed at any other future Information Days please contact the office (09) 845 5921.



FUNDRAISING AND VOLUNTEER NEWS

BE A BUCKETEER!

Musketeers, Volunteers – this year we are looking for Bucketeteers!

We have 500 collection buckets here in the office, all of which would like an outing on **Friday 3rd** and /or **Sat 4th September 2010** for our annual appeal.

We need to raise \$48,000 from our collections this year – we simply can't do it without your help.

So we need lots of bucketeteers who are willing to help fill these buckets. We are looking for bucketeteers who will help with our collections in malls, outside supermarkets and at other locations all over Auckland.

We need team leaders, as many as we can find who will help run a little collection at a convenient location for them. We provide the buckets and everything else needed, all they need to do is find a few friends, family or work colleagues to help them collect for the day. We promise its not that daunting, but if you can only help collect for a few hours somewhere that would also be greatly appreciated.

Alternatively be a bucketeer and take a bucket or two into your workplace and see if you can fill it there, or perhaps ask your favourite coffee shop if they will take a bucket. The buckets really don't mind where they go; they would just like to be filled with money that will go towards supporting the hundreds of people we work with on a daily basis.

To volunteer to be a bucketeer or if you need more information or ideas of how to get your workplace involved or what you could do to help please contact the office (09) 845 5921 or email nicola@msakl.org.nz, we would love to hear from you.



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 nicola@msakl.org.nz

FIELD WORKERS UPDATE

FROM ALLISON - RODNEY / EAST COAST BAYS

Sydney lived up to our expectations, we were on the run the whole time exploring new places in beautiful weather. The current balmy weather suits those with MS so hope you've been enjoying it before the winter sets in. Seeing eye dogs have been operational for some time. Under the Mobility Dog Scheme it is possible to have a dog trained up for your needs, whether it be for safety, support or any other reason. You have to be able to identify how this dog would benefit you and then go through the process of applying and an interview. There is also a possibility of funding for the dog. The dog will be trained up to meet your requirements. See the story on page 10. For more information contact your Field Worker on (09) 845 5921.



FROM BEA - MID AUCKLAND

Autumn is a second spring when every leaf is a flower. Changes in the seasons remind me of advice from an Acupuncturist, to keep the body warm internally by eating warm food instead of cold. Remember you can apply for the ENERGYWISE grant where you may get a 1/3 (up to \$1300 incl GST) off the installed cost Pink Batts underfloor and ceiling insulation. It's run by EECA and replaces existing EECA home insulation programmes. Better insulation means our homes are warmer, cosier, and easier to heat. Warmer, drier homes bring health benefits, especially for those with respiratory illness or other conditions derived from living in cold and damp houses. The website is: www.eeca.govt.nz or phone (09) 377 5328.



FROM DIANE - NORTH SHORE

With all the publicity surrounding stem cell research it is reassuring to find an official publication summarising the guidelines for people affected by MS. I have recently found on the UK MS Society website a public information booklet "*Stem cell Therapies in MS*" which has been produced by MS Societies for the UK, USA, Italy, France, Australia and the MS International Federation. Check out page 13 in the newsletter to access this hyperlink. I am looking forward to taking 4 weeks holiday from Monday 14th June returning to work on Wednesday 14th July. I'll be spending time in Adelaide and Canberra visiting my 2 sons and their families.



FROM DIANNE - SOUTH AUCKLAND

Here we are in June already! This year is flying by! Time to think about how we are going to cope with the winter ahead of us. Good heating! Plenty of warm clothes! Mulled wine! And Vitamin D3. Sounds like a plan. Don't forget to read about the good things in this issue that are happening down here in the South. We have a young man who is a personal trainer working with a group of people in Beachlands and getting wonderful results; and a caring, inventive brother, coming up with ways of making his sisters life easier while maintaining her independence. And of course we have some wonderful groups running that give us support and encouragement and exercise too. You are all welcome to join us. Take care.



FROM GEORGA - WEST AUCKLAND

I want to highlight a rehabilitation option called "Conductive Education" (CE). CE was developed by Professor Andras Peto a Hungarian physician. The only place in NZ that runs classes for adults is located at Tui Glen in Henderson, West Auckland. These once a week group classes have been beneficial for many people with different conditions, including MS, Parkinson's and stroke. For more information about these classes contact Inna at Integrated Neurological Rehabilitation Foundation, Ph (09) 836-6830 or e-mail admin@inrf.org.nz. See the article on Conductive Education on page 12 to get a better understanding of what it is.



FROM GLEN - CENTRAL AUCKLAND

These 3 words 'Biology of Belief' came into my busy mind today and it got me thinking how true that can be. My own experience about it is "one is what one thinks"... and/or "believes" I guess! I find it amazing when one manages to catch a random thought (either positive or negative) as it arrives and then watch it activate a feeling or emotion within! I then realise in wonder how a simple thought can so powerfully influence one's physical, emotional, mental or spiritual well-being. Of course an avenue one could use to change this pattern is Meditation... Yes! Let's give it another try!



SNIPPETS AND WEBSITES

NEVER TOO OLD

This programme focuses on balance and coordination. It is held every Monday, Tuesday, Thursday and Friday from 9.30am till 10.30am at the AUT Sport & Fitness Centre on Akoranga Drive in Northcote. All facilities are accessible. For programme information, contact Dennis or Jacqui on **(09) 921 9747**

FITDAY

FitDay is a free online diet and weight-loss journal. The FitDay journal allows you to track your diet and activities with no guess work. This lets you take control of your diet and fitness and achieve your fitness goals. You can request a free journal by visiting the website and filling in the details under 'About FitDay'. Please visit www.fitday.com or you can email them at feedback@fitday.com for more information on the product.

COLD HANDS AND FEET

One of our members showed us these Alpaca socks and fingerless mittens which would be good for the winter as many of our folk with MS feel the cold. Visit www.riverdalealpaca.co.nz or www.incasecrets.co.nz

SOUTHERN CROSS TRAVEL INSURANCE

Another member who is travelling overseas to the United States and Canada got a good travel deal from Southern Cross Travel Insurance online. It cost a further \$50 to insure for MS on top of the general policy. It's often hard to find an insurer who will cover MS as a pre-existing illness. You might want to check them out. Visit www.southerncross.co.nz/travel-insurance-new-zealand for more information.

GOOD READING

A couple of people have recently borrowed a book from our library called "*Mental Sharpening Stones – Managing the Cognitive Challenges of Multiple Sclerosis*" written by Jeffrey N. Gingold, (Publisher Demos Medical Publishing) who has MS himself. This informative book outlines the tools that Jeffrey and other people with MS use to manage and overcome this symptom. Each chapter outlines the particular strategies used to maximise cognitive strengths. Some members found the book so helpful that they have bought their own copy from Borders bookshop, so you may want to check this out.

Diane – North Shore

SAILABILITY

This website is dedicated to providing opportunities for children and adults with disabilities to learn to sail, or just to experience being in control of a sailing boat. They have sailing programmes suitable for almost anyone regardless of the level of their disability or sailing skills. "Our aim is to provide people with disabilities the opportunity to sail in safety and to experience adventure and freedom – building mobility, self confidence and pride through achievement". Visit www.sailabilityauckland.org.nz

KIWI TRAVEL & TOURS LTD

Are a travel company that cater for senior travellers, with one very important point of difference, they have a nurse accompany some of our outbound tours (called Kiwi Care). They have just completed their first Kiwi Care trip to Norfolk Island and it was a resounding success. One member had MS, several people required wheelchairs and walkers but that didn't stop them from having a great time. They would love more people to take advantage of what they offer. www.kiwitravelandtours.com

WALKING IS OVER-RATED

This is a website which has recently been created by a young Auckland man. It provides information on disability news, views and reviews. It also gives information on wheelchair accessibility in several Auckland café's and restaurants. Visit www.walkingisoverrated.com

DISABLED SNOW SPORTS (aka Adaptive Snow Sports NZ)

Is all about adapting equipment and lessons and providing accessible support systems to allow people with a wide range of disabilities to take to the snow and experience the freedom of snow sports.

Snow Sports NZ is the national advocate for Adaptive Snow Sports, supporting programmes at New Zealand's alpine resorts and the further development of snow sports in NZ. Their aim is to remove participation barriers and encourage people with disabilities to get involved. Visit www.disabledsnowsports.org.nz or email them info@disabledsnowsports.org.nz

Do you know of any helpful websites or organisations that others may be interested in? If so contact us on (09) 845 5921 or email editor@msakl.org.nz

MY STORY

MY AMAZING BROTHER...

For a brief overview my name is Kim, I'm 35 years old and was diagnosed in July 2000 at the tender age of 26. Life has had its challenges and ups and downs but for me I have decided that 2010 is my year. I'm taking the control back! It all began on February 7th.

This is the day that changed my life and I owe it all to my brother. As a surprise he presented me with a car. But not just any car. He bought it in December and spent the next 6 weeks working on it. He has converted it to hand controls, he has put a hoist in the back that operates by remote control to lift me in and out of the car, he removed the front seat so my wheelchair fits easily in beside me (even changing the position of the seatbelt so I can strap in the chair so it won't fall on me when driving) and even – get this – an air compressor fitted to the floor so I can pump up my chair wheels. Everything needed has been thought of.



He also decided that I needed a winch in my bathroom for those "just in case" moments. So my Dad and my brother installed one in my bathroom that runs from the toilet to the shower. Not needed at present as I am having success with transferring from my wheelchair but invaluable in the use of picking me up easily and quickly from the floor on the odd occasions when I fall, (something that came in handy just a few days ago).

Because of this unselfish generosity, something inside me clicked and I decided the best way I could thank him was to start putting myself first and have also (with his guidance and advice as well as references from Dr Jelinek's books) adopted a new diet and eating regime. I am limiting the amount of meat meals I have to two or three a week and eating a lot of whole raw foods. I still use cows milk, cheese and eggs but I have found by cutting back on meat meals my energy levels have increased, I feel generally more settled and not as "heavy" as I did.

Another bonus which I wasn't aiming for but has happened anyway is I've lost weight. Something must be working because I am the happiest, most content and settled in my life at the moment that I have ever been and I just can't stop smiling. Positive thinking and meditation also play a big part. So what is it I'm trying to say? Try it, what have you got to lose?

I have also found a beauty therapist who comes to you in your own home. So now I am having regular massages. This makes things easier than you having to make your way to them, and she gives a great massage! Lusia is her name and all details can be found on her web site at www.mobilebeauty.co.nz Do check her out. She is great and it doesn't cost the earth.

By Kim Robinson

RETREAT 2010

MS Auckland Region will again be running a week long retreat programme facilitated by Professor George Jelinek, Dr Sandra Neate and Dr Craig Hassad. This years retreat runs from September 13-17th and the venue will again be the Mana Retreat Centre on the Coromandel. Costs are NZ\$1,500 per person and NZ\$2,600 per couple (partner or support person) The Retreat is open to all people with Multiple Sclerosis.

For further information contact gary@msaki.org.nz or ring Gary on (09) 845 5921

WELLBEING INFORMATION: HOW MEDITATION CAN HELP REDUCE FATIGUE

Meditation is becoming more and more accepted throughout the scientific world as one of the most beneficial techniques for boosting immunity and reducing some symptoms of chronic illness such as MS fatigue.

Meditation, in its simplest form, is an age old practice of calming the mind and creating balance in the body. This balance can let your body ease its way into providing relief from fatigue. Meditation itself will not make the fatigue go away but a regular daily practice will build up the body's immunity and its ability to counteract the debilitating effects of chronic fatigue experienced by many people who have MS.

The problem for many of us is that we don't know how to meditate, we think we don't have the time and/or it is a scary concept because we don't know much about it.

Firstly, there is no right or wrong way to meditate. Meditation means to focus or exercise the mind. So long as you are focusing your mind on some sort of object, be it the breath, a short phrase (sometimes called a mantra), or the image of something spiritual then you are meditating and creating a practice which will be benefiting your mind and body.

It is true that you can meditate when you walk, sing, paint, dance, do the dishes etc and this is a true art. But by creating a formal practice of meditation we are giving our minds and bodies a chance to restore and rejuvenate. Resting to create more energy.

Another hurdle that stops many of us from meditation is that we think we don't have enough time. This is never true! It's just that we have to prioritize. It's just that our minds are like untrained puppies and resist wanting to sit still. So we can always find an excuse of something that is more important.

The most effective way to create a new habit of meditation is to give yourself 5 minutes at the same time of each day. I find first thing in the morning is the best time for me because then I have done my practice and I know that I don't have to try and squeeze it in somewhere else during the day.

Five minutes is a really good amount of time to start with. If you can sit quietly for 5 minutes every morning for three weeks I am sure you will notice

some difference in your daily life. (I can not tell you what the difference will be but I can guarantee that you will notice something). Go on, give it a go!

One of the main things that you will notice when you meditate regularly is that you hear what the body needs. So if you are giving yourself time to sit quietly first thing in the morning then you are creating the space to check in with yourself. Giving you the time to become friends with yourself. When you do this you can learn to take better care of yourself. We all know that we are the only ones who can really do that properly.

So, how to Meditate?

Getting ready:

- Turn off all phones, appliances etc
- Get an alarm clock and set for 5 minutes (so you don't need to worry about when the time is up)
- Sit comfortably in a chair
- Allow the arms to rest comfortably on either side of the body
- Feel your feet on the floor or foot of chair. (If you can't actually feel your feet imagine that you can – so you are aware of your lower limbs)
- Gently close your eyes and have the eyes looking downward towards the body away from the brain
- Bring your awareness to the natural flow of your breath

Don't try and change the breath in any way, just feel the breath coming in and out of your nose. If, as you do this you feel anxious or slightly uneasy gently open the eyes but keep the gaze downwards.

Try to follow the breath from the moment you begin to breathe in through to the end of the inhale and then again from the beginning. Just keep breathing.

The mind will instantly start to think of more important things. Or start telling you this is a waste of time etc. Just let that thought go, let it float away and return to your breathing and start again.

Then, you may well start to feel sensations that are distracting you, again as though they are thoughts just recognise them and then let them go and focus again on your breathing.

And so it goes for 5 minutes continuously, gently bringing your attention and awareness back to your breathing. Allowing everything else to let go.

Source: Wellbeing Information MS Wellington Newsletter / Charlotte Hathaway

MOBILITY DOGS

“On the 13th of November 2009 my life changed forever. This was the day that I took ownership of my first ever dog.”

I had fallen in love with the idea of mobility dogs ever since I had seen the amazing things that they do on the mobility dog website. The website featured several different dogs helping people with things like getting dressed and doing the shopping. From this moment forward I decided that this was something that I wanted in my life.

Several people told me that a dog would be too much work for a person with a disability like mine. I promptly dismissed this notion because I figured, that unless you are doing something that you really enjoy there isn't too much point in living.

Unfortunately getting a mobility dog did not work out for me, but having made up my mind, the next port of call was the SPCA. I put in my application and eagerly awaited their response.

I'll never forget the day I got their response. I was told that there was no way that I could have a puppy from them because, being in a wheelchair, I couldn't take care of it. I disregarded this nonsense and looked for a puppy on Trade Me. After months of searching I found one that I wanted. I offered to pay above the asking price because I didn't want to be disappointed again. But again I found myself up against narrow-minded people who put forward the same argument as SPCA and said that there was no way that I could have their dog.

Just when I was about to give up, I found a dog breeder with five pure Labradors for sale. The asking price was more than I had budgeted, and they were newborns so the work required to make one into a mobility dog would be immense. However I am not one to back down from a challenge, I purchased my dog and began counting the days until her arrival.

Having Xas (Sass) has changed my life. In the short time that I have had her she has tested my patience several times, which has forced me to deal with my frustration in a positive way. My confidence has also grown and she reminds me that the best things in life are often the simplest. If I had listened to the people who said it was too hard, who can see that they were wrong by just one look at my dog, then I would have missed out on this amazing experience, and I would not even know what I had missed.

By Ben Robertson

Source: In Touch Autumn 2010

TRAINING WITH JACK HOLMES

Hi everyone, my name is Jack Holmes and I am a personal trainer helping people with MS. I have a degree from Auckland University in Exercise Science and I have been working as a personal trainer for 5 years. My goal is to teach and improve your function and understanding of your body. Nutrition, stress management and anything else is welcomed and can also be trained.

Classes only cost \$5, are an hour long, and are held on Tuesday at 10am and Friday at 10.30am at Formosa sports complex, Jack Lochlan Drive, Beachlands. The ferry at Pine Harbour may be useful, however the gym is 1km from the ferry terminal.

Everyone is welcome and I look forward to seeing you there. Please feel free to get in touch with me to discuss anything further. Phone 021 2PT JACK or email jackdanielholmes@gmail.com

Walking with Jack

“Jack came into my life sometime during February, by mid March a small group of us were “walking” with him as our personal trainer at Formosa. We are now halfway through a 10 week trial and what a difference it has made! Walking has improved out of sight even though we still have a long way to go. Some days we walk “prettily” according to Jack. Muscles have been found that haven't worked properly for years or have been just plain lazy. Clear explanations are given as to what this muscle does and why we need to work on it. Confidence has gone up, praise has been given and fun has been had by all while “walking with Jack”. I am now aware of what I do wrong and have become more conscious of how to walk properly. Thank you Jack for your knowledge, expertise, encouragement and patience.” – Linda Reid

Swimming with Jack

“Swimming, like walking with Jack has been just great as he explains everything so clearly and we are able to do so much more with the support of the water. The strengthening of the leg muscles has improved out of sight. I am wondering if we should become “water babies”. Thank you Jack you are our Champion. Also thank you to the MS Society for supporting us.” – Margaret Strachan



L to R – Jack training with Linda Reid, Margaret Strachan and Max Stacey

TREATING SPASTICITY

Spasticity can affect just a few parts of the body (focal spasticity), or it can manifest in multiple places (generalised spasticity). It can range from insignificant to incapacitating, with many levels in between. Spasticity can also increase and decrease. Many people with MS recognise increased spasticity as a sign of bladder or other infection, or of the increase in core body temperature that is associated with a fever or excessive exercise, or a full bladder or colon.

Other causes of increased spasticity include:

- Noxious stimuli such as a skin lesion
- A bladder or kidney stone
- Fractures
- Tight clothing
- Menstruation
- Psychological stress
- Extreme environmental temperature
- Hunger
- An MS exacerbation
- Treatment with some disease modifying or antidepressant agents

Maintaining range of motion can be done with a regular home exercise programme, home physical therapy programme or through a community-based exercise class. Ice has also been shown to reduce spasticity in some studies, and the application of local heat can aid in stretching, although there is a lack of consensus about how often and long to stretch.

Oral medications

A number of medications have been used to treat generalised spasticity. Although there is variability in response to and tolerability of different medications, most practitioners will suggest **baclofen** as a first-line agent. It works at the level of the spinal cord to help the body inhibit muscle movement. A number of studies have shown that baclofen is effective in reducing pain, improving gait and overall function, as well as decreasing spasm frequency.

However, baclofen can cause fatigue, dry mouth, dizziness and nausea and many people start on baclofen and say it doesn't work for them. However, if assessed carefully and consideration is given to dose and timing, the results may be more positive. A written regime, with slowly increasing doses that help a person with MS assess how baclofen affects them over a period of time, and

regular review can make the use of baclofen much more successful. Even so, some people with MS still find they cannot tolerate the dose of baclofen required for efficacy because of the side effects.

Another medication clinicians frequently prescribe is **tizanidine**. Again starting at a low dose, tizanidine appears to be particularly effective for painful spasms at night. Like baclofen, it can cause sleepiness, dry mouth, dizziness and fatigue.

Diazepam is also effective in treating spasticity in some people. It appears to have a greater risk of causing sleepiness and muscle weakness, and it has the potential for dependence and addiction which can affect adherence.

Dantrolene can be used for spasticity and it works at the level of the muscles to limit contractions. Besides sharing most of the side-effects of diazepam, baclofen and tizanidine, dantrolene also requires frequent laboratory monitoring to ensure the medication does not damage the liver. As a result, dantrolene is not prescribed as frequently. Other medications that may be prescribed include **clonazepam** and **gabapentin** although again, side effects can be problematic.

Local treatments for spasticity

For those with spasticity affecting a small area (focal spasticity), or who do not get relief from oral medications, local injections of **botulinum toxin** or **phenol** into the muscles can improve quality of life.

A typical example of spasticity treatable with botulinum toxin would be the overactivity of muscles that flex the wrist, reducing the ability to reach and grasp objects. Making those muscles weaker can improve both function and pain. There are two types of botulinum toxin, type A, known as Botox in the United States and Dysport in Europe; and type B, Myoblock. A local injection of botulinum toxin can last 3-6 months and make functional activities easier to undertake.

With both phenol and botulinum toxin, the effects are temporary and may require frequent injections. Also, individuals can build up antibodies to the botulinum toxin over time, making them ineffective. Some people are able to switch from the type A toxin to type B to prolong the therapeutic effect. The most appropriate treatment plan usually includes work with a physical and/or occupational therapist after the injection to improve functional movement of the affected area.

Source: Momentum NZ The Otago MS Newsletter / Issue 6 April 2009

CONDUCTIVE EDUCATION

Louise Gardner and 'Conductor' Erzsebet Gordon write about how Conductive Education can help MS. Louise, 43, was diagnosed with secondary progressive MS in 2007. She lives near Tiverton in Devon with her 'wonderfully supportive husband' Phil and four year old daughter Lucy.

I go to the immensely supportive South West MS Centre in Exeter and have tried a range of therapies with them, including Vibrogym and other exercise equipment. Even after many months of working on my fitness level, I was still using a stick to walk and my posture was getting worse. Also, my sense of balance was quite badly affected, I had lost control of my left leg and foot, and was experiencing severe muscle stiffness and spasticity in both arms and legs and was also falling on a regular basis.

Before the MS diagnosis, I had been a reasonably fit and active person so was concerned that I was destined for a wheelchair and felt rather helpless at times, especially when overwhelming tiredness set in. I used to have a recurring dream that I was running with the wind blowing my face. But I knew it was just a dream.

An Opportunity Not To Be Missed

Then one day I read in the Centre's newsletter that they were offering Conductive Education which could help improve the walking ability of people with MS. I phoned immediately as I didn't want to miss this opportunity. I met Conductive Education practitioner Erzsebet Gordon who was trained as a 'Conductor' at the Peto Institute in Hungary. She explained to me what it was and how it could help me. Conductive Education aims to rehabilitate children and adults affected by damage to the central nervous system due to a range of conditions. Peto believed that, despite the damage, the nervous system still possesses the capacity to form new neural connections. The 'conductors' devise a series of exercises that aim to retrain the brain to use different pathways to perform various tasks.

Toy Eggs, Spoons & Silly Walks

I was keen and attended for my first session at the beginning of June 2009. This was a 'getting to know you' session where Erzsebet assessed my particular needs. I then performed a series of exercises to the best of my ability. It was tiring but also exciting as I was told I'd be walking without a stick within a couple of months. I was given a set of exercises to practise at home as often as I could.

My main problem was with my left leg and foot but the exercises were performed first with my right leg, then the left. We used a range of simple props such as spiky rubber balls of various sizes, chairs at various heights, balloons, feathers and even a toy egg and spoon.

I didn't have too much trouble walking on my toes but when asked to walk on my heels I told Erzsebet I couldn't. She smiled sweetly saying, "That's why we practise". I understood that not visualising or trying a movement was not a good approach.

I often feel a strange sensation in my brain when I'm attempting a movement with a part of my body that is not functioning well, such as flexing my left foot.

I Was Walking Without a Stick in Three Weeks

After just three weeks I tentatively abandoned my stick and began to walk unaided. There are times when I've not done the exercises as much as I could or should have, but deterioration in mobility is an excellent reminder. I can't claim to walk well but I can certainly walk short distances without a stick. Some days I have a pronounced limp but I am standing straighter and many people have commented that I appear to be more upright.

The discomfort in my neck and shoulders, pains and spasticity in my legs and arms has all but disappeared. I am able to enjoy and take part in normal family life where I had previously felt excluded.

Apart from doing Conductive Education, I have also changed my diet, given up allergenic foods, and been treated with Acupuncture. My self-confidence has improved with my feelings about MS and what the future holds. Lately I have rented an adult tricycle and pedalled it along by the Tiverton Canal path. Now I can really get that "wind in my face" feeling. It's wonderful! Conductive Education is definitely the best thing I've done for my mobility. It's actually helped me make progress. If I had to pick one thing to do for MS, it would be Conductive Education.

Motivation & Stimulation From Working in a Group

Conductive Education sessions are run in groups so that the group members, receive re-enforcing stimuli from all directions – the conductor and also the other people in the group. They all hear what they are going to do, say it out loud, and then do it. A group also helps to reduce tension as individuals do not feel that all the attention is just focused on them.

A group helps individuals realise how much they are improving. People often don't notice their own improvements, but others in the group do notice and tell them. This is a great emotional motivator for everyone; learning can only take place when there is emotional motivation. This influences the sensory-motor system.

During each session, the conductor carefully monitors the participants, and sets short and long-term goals for each individual within the group. I pay a great deal of attention to reducing spasm, fatigue and tremor, improving gross and fine movements, learning breathing techniques to enhance speech, circulation and general well being, finding and maintaining the balance point, and improving the fluency and rhythm of walking.

The beauty of Conductive Education is that it encourages people to become active learners and be more and more independent. It gives them new purpose to their lives.

Source: *New Pathways Issue 60 – March/April 2010*

RESEARCHERS AGREE ON FUTURE OF MS STEM CELL RESEARCH

Today *Nature Reviews Neurology* publishes an international consensus on the future of stem cell transplantation research for people with MS, paving the way for more co-ordinated global research efforts and potentially better, and quicker, patient access to stem cell clinical trials.

The guidelines, which have been written and approved by some of the most well respected international MS researchers, as well as MS Societies from around the world, spell out hope for the future of MS stem cell research and debunk myths about overseas stem cell clinics claiming to cure the condition.

Professor Gianvito Martino from the San Raffaele Scientific Institute in Milan, Italy, and Professor Robin Franklin from the University of Cambridge, UK, are lead authors for the guidelines, which:

- outline the promise stem cell transplantation has shown in early stage clinical trials and ways they could be used to treat MS in the future

- describe the different types of stem cells that might be used to treat different types of MS
- detail methods of delivering these stem cell therapies into patients
- highlight best practice in conducting clinical trials to evaluate the safety and efficacy of stem cell therapies in MS

A stem cell public information booklet "*Stem Cell Therapies in MS*" produced in partnership by MS Societies from the UK, USA, Italy, France and Australia and the MS International Federation summarises the guidelines for people affected by MS.

Researchers have agreed that stem cells are likely to have a significant role to play in the treatment of MS, but also warn that expectations should be realistic.

Professor Gianvito Martino said: "At this stage it is unreasonable to claim that stem cells are a magic cure for MS. It is, however, likely that they will one day play an important role in treating the condition."

Professor Robin Franklin added: "It is only by working together will we get the answer as to whether stem cell transplants hold promise in the treatment of MS. The guidelines will help the research community get to that answer more quickly than we would by working in isolation."

The guidelines are the result of an international stem cell consensus meeting held in London in May 2009 organised by the MS Society in the UK and USA, and supported by MS Society of Italy, France, Australia and the MS International Federation.

Dr Jayne Spink, Director of Policy and Research at the MS Society in the UK, said: "The MS Societies around the world are in a unique position to facilitate co-ordination and collaboration regarding international stem cell research. This should help the research to progress more quickly."

She added: "We have coordinated the production of these guidelines along with the public information booklet to provide accurate information that should help counteract the confusion caused by unscrupulous stem cell clinics falsely marketing MS cures."

To view the information booklet please visit:

www.mssociety.org.uk/news_events/news/press_releases/guidelines.html

Source: www.mssociety.org.uk

VITAMIN D3 VITAL FOR IMMUNE SYSTEM

Vitamin D is vital in activating human defenses and low levels suffered by around half the world's population may mean their immune systems' killer T cells are poor at fighting infection, scientists said. The findings by Danish researchers could help the fight against infectious diseases and global epidemics, they said, and could be particularly useful in the search for new vaccines.

The researchers found that immune systems' killer cells, known as T cells, rely on vitamin D to become active and remain dormant and unaware of the possibility of threat from an infection or pathogen if vitamin D is lacking in the blood.

"When a T cell is exposed to a foreign pathogen, it extends a signaling device or 'antenna' known as a vitamin D receptor, with which it searches for vitamin D," said Carsten Geisler of Copenhagen University's department of international health, immunology and microbiology, who led the study.

"This means the T cell must have vitamin D or activation of the cell will cease. If the T cells cannot find enough vitamin D in the blood, they won't even begin to mobilise."

Scientists have known for a long time that vitamin D is important for calcium absorption, and that there is a link between levels of the vitamin and diseases such as Cancer and Multiple Sclerosis. "What we didn't realise is how crucial vitamin D is for actually activating the immune system – which we know now," Geisler wrote in the study in the journal *Nature Immunology*.

Most Vitamin D is made by the body as a natural by-product of the skin's exposure to sunlight. It can also be found in fish liver oil, eggs and fatty fish such as salmon, herring and mackerel, or taken as a supplement. Almost half of the world's population has lower than optimal levels of vitamin D and scientists say the problem is getting worse as people spend more time indoors.

Geisler and his research team said the findings offered much needed information about the immune system and would be of particular use when developing new vaccines. "This is important not only in fighting disease but also in dealing with anti-immune reactions of the body and the rejection of transplanted organs," they wrote.

Active T cells multiply at an explosive rate and as well as fighting infection, can also mistakenly attack the body itself.

After an organ transplant, for example, T cells can attack the new organ as a "foreign invader", and in autoimmune disease, hypersensitive T cells mistake parts of the body's own cells as threats, prompting the body to attack itself.

Geisler said there were no definitive studies on the optimal daily vitamin D dose but some experts recommend 25 to 50 micrograms or up to 5,000 i.u. per day for days out of the sun.

Source: *Stuff.co.nz* 08.03.2010

EXERCISE HAS PROTECTIVE EFFECT ON BRAINS OF MS PATIENTS

Highly fit people with MS who do regular aerobic exercise perform significantly better in tests for cognitive function than those who are unfit, showing that exercise is good for the brain. Also, MRI scans showed that the fitter MS patients showed less brain damage, as well as a greater volume of vital gray matter.

The study involved 21 women diagnosed with relapsing-remitting MS. They were compared with 15 age and education-matched healthy female controls. The study assessed fitness, cognitive function, and structural changes in all participants.

In order to measure fitness levels, the participants underwent a VO2 max test, in which they roped a stationary cycle until they felt exhausted. During the test, they breathed into a mask which measured their oxygen consumption.

All the women also took a variety of tests designed to evaluate cognitive functions, such as processing speed and selective attention. In one test participants had to write down in one minute as many words as they could think of that began with the letter F. As expected, all the MS patients did much worse than the healthy controls on the tests of brain functioning, and showed more deterioration in their brains as revealed through the MRIs. However, there were significant differences between the more aerobically fit MS patients and those who were less fit.

"We found that aerobic fitness has a protective effect on parts of the brain that are most affected by Multiple Sclerosis," said Ruchika Shaurya Prakash, lead author of the study and assistant professor of psychology at Ohio State University. "As a result, these fitter patients actually show better performance on tasks that measure processing speed."

Source: *Brain Research*, February 20th 2010

BOOK REVIEW

THE ULTIMATE STRESS BUSTER

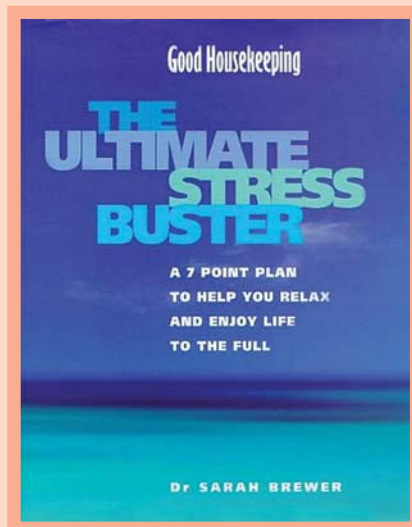
By Dr Sarah Brewer

The Ultimate Stress Buster by Dr Sarah Brewer is a self-help book which gives a clear explanation of how and why stress affects our lives and gives practical activities on how to manage it.

It will help you to identify the signs and causes of stress and by answering the questionnaire you can find out the level of stress that you are living under.

The advice given involves changing various aspects of your life, these include diet, exercise, learning to relax, alternative therapies and learning to organise your life more efficiently. With quick-fix solutions and long-term strategies this is a highly practical approach to the problem of stress.

Review by Rachael Turner-Ford



RECIPE CORNER

MIDDLE EASTERN VEGETARIAN SOUP

When you need a good hearty meal to warm you up from the inside out. Serves: 8-10

Ingredients

- 2 tbsps olive oil
- 1 large onion – chopped
- 2 cloves garlic – crushed
- 2 tbsps grated fresh ginger
- 2 medium sized carrots – peeled and chopped into small pieces
- 2 medium potatoes – peeled and diced into 1/2-inch cubes
- 4 medium tomatoes – chopped
- 1 cup finely chopped coriander leaves
- 7 cups water
- 2 tsps salt
- 1 tsp pepper
- 1 tsp cumin

Method

1. Heat oil in a saucepan; then stir-fry carrots, onion, garlic, and ginger over medium heat for 8 minutes.
2. Add potatoes, tomatoes, and coriander leaves and stir-fry for 5 more minutes.
3. Add remaining ingredients and bring to boil.
4. Cover and simmer over medium-low heat for 1 hour or until the vegetables are well-done. (Serves from 8 to 10)

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



For a variation to this recipe you can leave the peels on the Potato to enjoy a more rustic flavour and texture. You can also add other vegetables ie. Courgettes or Mushrooms.

FREE CHILDREN'S THEATRE TICKETS

We occasionally receive free theatre tickets to children's productions. Please contact us if would like to be added to the mailing list. You can contact the office on (09) 845 5921 or email editor@msakl.org.nz to update your details.

STUDY SUGGESTS PEOPLE BORN IN APRIL MOST AT RISK OF MS

Scottish scientists have discovered that babies born during April are at a higher risk of being diagnosed with Multiple Sclerosis (MS) later in life.

The results of the study, reported in the Sunday Times Scotland, suggest that mothers pregnant during the dark autumn and winter months were most likely to give birth to those who would develop the condition. The Glasgow researchers suggest that a mother's lack of exposure to sunlight during her unborn baby's development may explain the results, published in the European Journal of Neurology. Vitamin D is produced through exposure to sunlight and has been linked to genes thought to be associated with MS. Scientists have suggested that a lack of vitamin D could trigger a predisposition to MS in a person's genetic makeup. Director for MS Society Scotland, David McNiven, said: "These intriguing results add weight to the evidence that the environment, and in particular sunlight, plays a part in MS and we're pleased scientists are piecing together the complex puzzle of what may cause this condition."

Source: http://www.mssociety.org.uk/news/press_releases

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 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. There is no meeting in July, the next meeting is the 5th August. 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.