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EDITORIAL

Our Annual General Meeting is looming and we welcome all members (see details below). We are planning to screen the TV3 *Open Door Documentary on MS* that features some of our members. This will also be screened on Monday 26th April at 6.10pm on Freeview Channel 7 (Sky channel 97).

Subscription Invoices for this year will have reached you by now and we kindly ask that you pay subscriptions promptly to save us the cost of sending out reminder letters.

We are putting out an appeal in this Newsletter for many more people to help us with our Street Appeal this coming September. The more people that help us the more funds we will collect and this event is becoming increasingly important to our fundraising programme.

Below are some dates for your diary:

Annual General Meeting – Saturday 17th April 2010

Institute of Chartered Accountants, Remuera

MS Mini Conference – Saturday 15th May 2010

Institute of Chartered Accountants, Remuera

Street Appeal Info Evening – Wednesday 26th May 2010

Mt Albert Community Centre, FREE drinks, nibbles and a prize draw on the night

Although we are committed to tight financial control this year we are also determined, within our means, to create new opportunities for our members. Amongst our plans is a re-vamp of the Gym network to get better deals for our members and our Mini-Conference in May. Later in the Year there is a plan to bring the Focus on MS event run by National Office bi-annually to Auckland. Watch this space!!

Gary



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 year's 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@msakl.org.nz or ring Gary on (09) 845 5921

PETA MATHIAS – MS AUCKLAND REGION'S FIRST AMBASSADOR

We are delighted to announce that chef, author and broadcaster Peta Mathias has recently been appointed an Ambassador for MS Auckland Region.

The role of an ambassador is a key role for the society, while this is a new role for us, charities have been using high profile individuals to help promote their work for many years. Individuals willing to become Ambassadors are publicly endorsing the work of the Society and happy to encourage others to do the same. As a result of their public profile they are able to raise the profile of our work and consequently make the general public more aware of MS and the work of the Society.

Peta Mathias

Peta Mathias is a respected and prolific New Zealand chef, author and broadcaster, who now builds on the culinary travel experience with her gastronomic tours in the South of France, Morocco and India. Having started off her culinary love affair in Paris with her restaurant 'Rose Blues' in the 5th arrondissement, she returned to New Zealand ten years later to teach, cook and write.



For twelve years Peta presented the prime time travel/food shows 'Taste New Zealand', 'Taste Takes off' and 'A Taste of Home'. Peta's initial writing focused on gastronomic travel books. However Peta has more recently ventured into new territory with 'Can We Help It If We're Fabulous?' a book about women, which came out in August 2008, followed by 'Just In Time To Be Too Late – Why men are like buses' published in November 2009 and hit the best seller list within a week.

Peta first became involved with MS Auckland Region in 2008 where she joined Raylene Ramsey for the successful "Taste of Peta" fundraising lunch. Then in 2009 she chose to celebrate her 60th birthday by raising funds for the Society with an elaborate party at the Auckland Museum. Although there is no immediate personal connection Peta is passionate about the work of the Society and the impact MS has on individuals.

"The thought of being diagnosed with Multiple Sclerosis would be tough. The work the Society do to improve the quality of life of those living with MS is fantastic and it is a privilege to be involved with them and the work they do."

We are always keen to talk to "public figures" who may be interested in supporting the work of the society. If you know anyone who you think may be interested let us know.

FUNDRAISING AND VOLUNTEER NEWS

STREET APPEAL INFO EVENING

We are currently planning for this years Street Appeal, to be held on Friday 3rd and Saturday 4th September and have already secured many locations across Auckland to collect.

ALL WE NEED NOW IS THE PEOPLE TO COLLECT AT THEM!

As we say every year, the more people that are willing to help us collect, the more collection points we can man and consequently the more money we can raise. Last year we raised over \$35,000 from our collections but there were many places we could have collected but didn't simply because we didn't have enough people to help out.

So please consider getting involved or even finding some friends or family or work colleagues to help out.

We are having an informal **Cheese & Wine information evening on Wednesday 26th May** at the Mt Albert Community Centre to share some information on how easy it is to get involved, what's involved in being a Team Leader and leading a collection and tips on how to get other people to help!

This will start at 7.30pm will only last for just over an hour and refreshments will be provided. Also everyone who attends will have their name put into a draw (on the night) to **win an Apple Ipod Shuffle**.

The more Team Leaders we can recruit the more successful the appeal is. Without team leaders it is difficult for us to ensure a collection runs smoothly as it is obviously harder for us to organise numerous rosters and collection materials for multiple locations from the office.

If you would like to come along and find out more and talk to people who have been involved previously please RSVP to Nicola at nicola@msaki.org.nz or call (09) 845 5921 by Friday 21st May.



BECOME A FAN ON FACEBOOK!

MS Auckland Region has finally embraced the social networking phenomena that is Facebook and have set up a page which will enable us to stay in touch with both fans here in Auckland, but also much further afield.

We will post photos, updates, event information as well as links to other sites etc.

It is also a great way for people to ask others questions, raise topics and have discussions amongst other fans.

For those of you that already have your own Facebook account, check out our page by entering this link into your web browser: <http://tinyurl.com/yd77cey>

Alternatively you can type in Multiple Sclerosis Auckland Region into the search box on your Facebook page and we should pop up.

If you don't already have a Facebook page, its **free and easy to sign up** – just visit www.facebook.com and follow the simple sign up procedure.

Share this around your friends as well and encourage your existing Facebook friends to become fans.

Once you become a fan you can click on the "suggest to friends" link underneath our logo and circulate amongst your friends.



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

FUNDRAISING AND VOLUNTEER NEWS

ANNUAL MS BBQ

We all enjoyed a great BBQ on Saturday 27th February in Coatesville with balmy weather, shade and sun, great food and company. The young ones were also able to have a swim in the pool. We had a close encounter with Judy's horses and loved meeting the new foal.

Our very special thanks go to Judy and Graham from us all at MS Auckland Region for opening your home up to us again for another fantastic BBQ. Everyone had a lovely time as you can see from the photos.



OPEN DOOR DOCUMENTARY

TV3, Sunday 14th February

That was good talent with a clearly told story. TV can be a difficult medium to work in for some people but that is a fine end result. The part of the story that got me (as a future primetime sell) was the vitamin D part. Cutting back on slip, slop, slap in New Zealand I'm sure would get up someone's back. That is why off-peak was better for you.

Ken Burns

ENTERTAINMENT BOOK

Entertainment Books are now in the office – don't miss your chance to get your copy of this fantastic book! With thousands of dollars worth of savings off dining, cafes, attractions and retail across Auckland you can't afford not to get a copy. Books are only \$65 + \$5 postage and for every book sold MS Auckland Region receives \$13. For further information or to order your copy please see the enclosed flyer.

WELCOME FLEUR

Fleur Drewitt is a Physiotherapist from Rope Neuro Rehabilitation, a private community-based neurological physiotherapy practice based in Mount Eden.

Fleur graduated from Auckland University of Technology and started her working career at Auckland Hospital progressing to senior level Neurology and Neurosurgery.

She has recently been practising in London, UK, working within a community neurological team, specialising in long term Neurodisability, including Multiple Sclerosis. This included managing a project to establish a fully accessible gym service to enable disabled clients to exercise in mainstream gyms.

She has experience in a wide variety of settings with various age ranges and cultural backgrounds and has a special interest in postural management splinting/casting and exercise therapy.

She is excited to join the West Auckland pool group to support existing and new members of MS Auckland Region to access West Wave for fitness, strengthening and social support.



ATTENTION NORTH SHORE RESIDENTS

EXPIRED/UNUSED MEDICATIONS

Most expired/unused medications returned to pharmacies are simply sent to medical waste companies for safe destruction. Albany Village Care Chemist is now working with Medical Aid Abroad to send these medications to developing countries, where they can be put to good use. We are also more than happy to collect any returned medications from surgeries in the North Shore area.

Please feel free to contact Lisa Multrus for information on 09 415 9676 or e-mail: albany@care-chemist.co.nz (Any expired sealed dressings would also be appreciated).

We make a living by what we earn.

We make a life by what we give.



Payroll Giving – How it Works

The Payroll Giving Foundation helps employees and employers support good causes in the most tax-efficient way – by giving directly from their pay.

Step 1

It's so easy to set up. Just fill in one form at www.payrollgiving.org.nz. We will let your payroll department and chosen charity know you want to start giving and this should start in a few weeks.

Step 2

You get **33½%** back on your donation in your pay. Your chosen charity automatically receives your gift tax-free when you give directly through your pay and you get a tax credit.

Step 3

Maximum benefits for your charity. Regular giving from your payroll allows charities to plan confidently for the future. Help your favourite charities, community organisations or school.



Get started today at www.payrollgiving.org.nz

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@msaki.org.nz

FIELD WORKERS UPDATE

FROM ALLISON - RODNEY / EAST COAST BAYS

By the time you receive this I will have had a week's holiday in Sydney. We are looking forward to going to the Blue Mountains and also out on the harbour. I don't expect the weather to be any cooler as it is pretty hot over there. A new service has been contracted by the Government to Taikura Trust for people with disabilities who live in damp houses. They will assess the situation and financially assist with whatever is appropriate to ensure that the houses are made as dry as possible for the winter. This applies to people renting as well. It does not apply to people in Housing NZ properties as they have their own Government contract. Please contact your Field Worker if you wish to discuss this further.



FROM BEA - MID AUCKLAND

I've been making an effort to live more in the present, when we get busy or 'worry' we can become easily stressed or anxious. One way of calming the mind is by the use of meditation or relaxation tapes. Bev Sylvester who ran one of our workshops last year suggested that if we notice our minds wandering in meditation to say a word, maybe 'thinking', and taking a few deep breaths. She found it stopped the mental chatter and helped her meditation. I have also found this useful whether it be in meditation or when driving between visits it just brings my focus back to the present and keeps me in a more peaceful state during the day. You might want to try some word of your own followed by deep breaths. Have fun with this and try not to be too strict on yourself.



FROM DIANE - NORTH SHORE

Hi everyone. I have just spent several days down in New Plymouth and had a magical time. The whole time we were there Mt Taranaki was in full view with no clouds at all. It really is a powerful presence in the area. It is more pleasant with the cooler weather and I know many of you have been struggling with the heat over the summer. However the cold can also be challenging for some of you so if your house isn't well insulated now is the time to do this and make sure you keep warm in the autumn weather to avoid colds. If you haven't heard from me for a while do get in touch as I'd love to hear from you.



FROM DIANNE - SOUTH AUCKLAND

I want to take this opportunity to thank some very special, caring people. These people come along to the Papatoetoe pool group every week; rain, hail or shine and work with, encourage and laugh alongside those of us attend. Without these people, the sessions simply would not happen. So, a big THANK YOU goes to our volunteers Vanessa, Robyn and Gerry under the watchful eye of Sandra Blewett. Thanks girls! You are fantastic! And we appreciate your efforts. If any of you wish to join this inspirational group of "pool goers" either as volunteers or to take part then just come along. We meet at the Papatoetoe Pool in Sutton Ave on Wednesday mornings at 10.30am with classes commencing at 11am and finish at noon.



FROM GEORGA - WEST AUCKLAND

Hi everyone. One place which is worth taking note of is the 'Disability Resource Centre'. Their main functions are to provide disability related information and advice and they have a wide range of disability products and equipment for viewing and purchase. Check out their informative website at www.disabilityresource.org.nz to see the type of products they have. They are located at 14 Erson Avenue, Royal Oak, Auckland and their phone number is (09) 625-8069. So if you are looking for something in the disability field you should remember this option.



FROM GLEN - CENTRAL AUCKLAND

For those of you who are involved with the Taikura Trust under 65 Needs Assessment Service we are endeavoring along with their staff to be included more, to support in person those of you who would find the process exhausting or stressful. Remember the Field Workers are available whenever possible to be present at these assessments... We are a phone call away!



Pregnancy on the horizon? If so, ensure prospective mums have their Vitamin D levels checked, latest research in the UK reports the importance of the correct levels at the time of the fetus developing. (Evidence suggests that about 25% of babies there have developed fetal rickets – astounding in this day and age).

MY STORY - LOTTERY GRANT

Recently, I was lucky enough to be approved for a vehicle from the Lottery Board, with Allison Wheeler's help and recommendation. I have not driven in over eight months, with numerous broken bones over the last three years, I have become very isolated and dependant on people for rides, it has been very frustrating.



I have Motor Neurone Disease but have been a member of MS Auckland Region for over eight years, they thought I had MS in the beginning, this has affected my speech and walking, so I am unable to phone people and I rely on pen and paper for communication. I was approved in August 2009 I and started out by visiting the Drivers Assessment people to get their guidance on suitable cars, I wanted a small one that was nice and easy to park. It turns out now that I need a hoist arm in the back, so bye bye to a nice small car.

I had to pass my drivers test to prove I could manage a car again, I was very, very nervous but I passed, my girls were not impressed as they hoped I would fail so they could keep me safe at home. I had applied for a car grant without telling them. I went looking at car yards and what a nightmare that was. Some were so sleazy, I finally stumbled onto the Wheels on Wairau website and saw they had some Toyota Raums coming in. I conversed with Phillip Heald by email, told him my situation and what I needed, he was so great, offering to bring the car to me to view but I chose to go to the yard and have a nosey at all the cars.

Phillip turned out to be so nice, friendly and helpful, he went out of his way to make the buying of a car so easy for me, he organised all of the tests required, took it out to Pakuranga for the Driving Assessment guy to have a check of it and see that it was suitable, brought the paperwork out to my home to sign and allowed me to pick the car up before the cheque was even sent.

I'd recommend anyone who is looking for a car to purchase one from Wheels on Wairau. My two sisters and brother in law have all bought cars from them in the last year and a half and all their cars have been great. Thanks to the Lottery Board I now have the freedom and independence again and I am so grateful to Allison for all of her continued help and guidance with everything.

By Tanyss Dykes

SNIPPETS AND WEBSITES

THE KNOWLEDGE LIBRARY

THE KNOWLEDGE LIBRARY provide in depth information on studies of general health topics. They are funded by the Ministry of Health and SPARC. They provide information on New Zealand based nutrition, physical activity and sport & recreation research and evaluation literature. The Knowledge Library currently includes information on more than 1800 pieces of New Zealand based research, 130 funders and 150 related projects. Please visit www.heha.org.nz for more information.

CHOW

Chow is a restaurant chain with restaurants in Takapuna, Auckland City and Wellington. The food is fantastic and is catered towards those on very special diets with specific dietary requirements. They offer specials including a 2 for 1 Monday. They also provide market fresh ingredients and free range foods. For more information please visit www.chow.co.nz

TELESTIK TS3700

TELESTIK TS3700 is a wheelchair accessory for those with limited finger, hand or shoulder strength. You can take it wherever you go. Telestik reachers are the lightest and most portable reachers in the world. For more information on the very popular Telestik please visit www.telestik.com

DIVERSITYWORKS PEER SUPPORT NETWORK

Diversityworks is an informal collective of people committed to shared support and learning in a social environment. The network uses a mix of online chats, social networking (blogs, forums, Facebook and Twitter), Skype and phone chats, texting and face-to-face meetings, to keep people in touch with each other. They also run workshops, with topics prioritized by network members. Peer support networks are very diverse, safe and friendly. Give it a try. Visit www.peersupport.diversityworks.org.nz for more information, you can also email them peersupport@diversityworks.org.nz or phone (09) 889 9015 or text 021 264 6154.

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

MULTIPLE SCLEROSIS NURSES AUCKLAND HOSPITAL

Multiple Sclerosis is the largest cause of neurological disability in young adults affecting woman 3:1 and most frequently symptoms and diagnosis occurs between ages 20-40. Symptoms can be variable and literature supports the idea that good management in the early stage of illness and support at the time of diagnosis has significant positive psychological impact.

At ADHB the MS team consists of Justine Simmonds (MS Nurse), Gill Willoughby (MS Trial Coordinator) and Fiona D'Young (MS Nurse & MS Research Nurse). We aim to support PwMS (People with MS) throughout their journey with their long term neurological condition. The MS specialist nurse is pivotal in providing a greater understanding of the condition, and by adopting an holistic, collaborative and coordinated approach can help people, where possible, reach their goals of self-management.

The MS Nurse role also involves acting as a kind of consultant, working with the GPs, other therapists, employers and with MS charities and also providing a resource for staff striving towards greater awareness and knowledge of MS in the health and social arena.

Justine and Fiona provide advice and support for PwMS in the Auckland area – from those newly diagnosed with MS, people starting Disease Modifying drug treatments or experiencing exacerbations, provide expert assessments of patient needs and ensure the appropriate link people are involved in the PwMS's care.

Gill heads up the MS research studies; helped by Fiona. There are currently 4 fully recruited studies running at ADHB (4 studies precise, BG12, Strata and TIME.). We will update you on new studies when they begin.

A New Zealand wide National Prevalence Study was completed in late 2008 which looked at surveying PwMS with the aim of gathering vital information about sunshine exposure, social impact etc. NZ is the only country thus far which has looked at the prevalence of MS in all provinces and this work will provide valuable information when setting up future services.

The MS specialist nurses would like to advise everyone that they have a very open door policy and they would like people to feel welcome to contact them should they have any issues or concerns. Please contact Justine Simmonds either via email, justines@adhb.govt.nz or phone (09) 307 4949 extension 25885.

FITNESS BOOSTS BRAIN POWER IN MULTIPLE SCLEROSIS PATIENTS

Exercise appears to protect the brains of people with multiple sclerosis, new study findings suggest.

Researchers assessed fitness, cognitive function and brain structural changes in 21 women with relapsing-remitting multiple sclerosis (MS).

Patients who were classified as being highly fit performed much better on cognitive function tests than less-fit patients. MRI scans also showed that higher levels of fitness were associated with greater volume of gray matter, which is linked to vital brain processing skills, and less damage in parts of the brain where MS-related deterioration occurs.

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

The researchers also found that fitter MS patients showed less deterioration of brain white matter, which are fibers that connect gray matter areas.

The study findings were released online in advance of publication in an upcoming print issue of the journal Brain Research.

Previous research has shown that exercise promotes production of proteins called nerve growth factors, which play an important role in the growth and maintenance of neurons in the brain.

"Our hypothesis is that aerobic exercise enhances these nerve growth factors in MS patients, which increases the volume of the gray matter and increases the integrity of the white matter. As a result, there is an improvement in cognitive function," Prakash said.

"For a long time, MS patients were told not to exercise because there was a fear it could exacerbate their symptoms. But we're finding that if MS patients exercise in a controlled setting, it can actually help them with their cognitive function," she added.

Source: *The Palm Beach Post Health* www.palmbeachpost.com/health

LAKE TAUPO 100KM SOLO WALK

On the weekend of the 20th of February Fiona Williams (one of our North Shore members) competed in Great Lake Relay, a mind-boggling 100km walk around Lake Taupo, raising money for MS. So far she has raised over \$1,500. Here's her story:

In the week leading up to my big challenge I had a sore knee – an old injury rearing its head after many years, and I was unable to train as much as I had hoped. I was concerned about my fitness level for what I knew was to be a gruelling event. I awoke at 3 a.m. on the big day, went for my swim, headed off to work, and set off for Taupo at 1.30 p.m. arriving at 5 p.m. The hours before the walk whizzed by and suddenly there I was at the start line, with a similar feeling to that of subsequent births after the first – i.e. “why the heck am I doing this again?”

My elder daughter (Laura) and younger son were chanting “Ginja Ninja” (my event name) as the countdown started. We set off at a fast pace and although the night was cool the first 25 km were warm and reasonably comfortable. It was dark and rather lonely once I left the lights of Taupo behind but Laura and her boyfriend stopped regularly to ask if I needed anything and to find out how far ahead they should wait.

I had a cup of tea at 25 km and headed back out on leg 3. The trucks were whizzing past very close to me and gave no signs of slowing or giving me room so I ate diesel fumes and had my hat blown off a number of times. I had been awake for 24 hours and was feeling a little dizzy under the headlamp light which was a little disconcerting.

By 4 o'clock the temperature had dropped rapidly and the fog came down around me, freezing my arms so that I was numb from the elbows down, I could no longer answer texts as my fingers were swollen, frozen sausages.

After a brief stop for a bowl of porridge at 7 a.m. off I went again, with high hopes of bettering my time from last year (16 hours and 15 minutes). However, as the fog lifted and the sun came out, I was to experience the most difficult walking conditions so far - in searing heat.



Fiona supported by her daughters

When I returned to the 75 km mark, I was in pain – my knee was playing up and it had referred pain to my hip which was grinding with each step. I knew then that I had to pull out all stops. I thought of the article in the North Harbour Times and my pledge to donors on my online fundraising site, and I knew I just had to go on no matter what.

At 85 km my daughters and Laura's friend Deb decided to take turns to walk with me and keep me company, and I got to the final turn at 88.5 km, exhausted and on the point of collapsing.

The last 12 km seemed insurmountable, in the heat with no relief in terms of shade. I thought I was going to have to drop out but Laura kept encouraging me by telling me how close I was to the end. She had been marvellous as a support person.

With 8 km to go, my shoes had to go and my elder son turned up to walk the remaining distance with me, taking off his T-shirt and dousing it in icy water and putting it round my neck. He also squirted my mouth which was burnt from the reflection off the road, and my feet which were sizzling. He and his mate passed comment that I was a true 'coasty' walking the last few km in bare feet, and at that stage supporters were lining the road waiting for their competitors and teams and were cheering for my effort which was heart-warming.

When I saw the 'Taupo 3 km' sign, I knew I would crawl it if need be and as we turned the last corner with about 200 metres to go, it was a feeling of exhilaration and achievement. I hobbled across the line with Gareth on my left and Laura on my right gripping my hand tightly and a great welcome from the onlookers, at 16 hours and 50 minutes. I had not beaten my record, but I made it and the thought of the money raised for MS made it all worth the effort.

Next year it's the relay for me!!! Thanks to all who supported this very worthy cause! And thanks to my local 'Curves' gym and the clients there their ongoing support for me in my fundraising endeavours.

Fiona Williams



Crossing the line, after 16 hours and 50 minutes, with her daughter and son

HOW TO READ HEALTH NEWS

If you've just read a health related headline that has caused you to spit out your morning coffee ("Coffee causes cancer" usually does the trick), it's always best to follow the Blitz (a widely criticized telco) slogan: "Keep Calm and Carry On". On reading further, you'll often find the headline has left out something important, such as, "Injecting five rats with really highly concentrated coffee solution caused some changes in cells that might lead to tumors eventually." (Study funded by The Association of Tea Marketing).

The most important rule to remember is: don't automatically believe the headline. It is there to draw you into buying the paper and reading the story. Would you read an article called, "Coffee pretty unlikely to cause cancer, but you never know"? Probably not. To avoid spraying your newspaper with coffee in the future, you need to analyze the article to see what it says about the research it is reporting on. Bazian has appraised hundreds of articles for Behind The Headlines on NHS Choices, and we've developed the following questions to help you figure out which articles you're going to believe and which you're not.

Does the article support its claims with scientific research?

Your first concern should be the research behind the news article. If an article touts a treatment or some aspect of your lifestyle that is supposed to prevent or cause a disease, but doesn't give any information about the scientific research behind it, then treat it with a lot of caution. The same applies to research that has yet to be published.

Is the article based on a conference abstract?

Another area of caution is if the news article is based on a conference abstract. Research presented at conferences is often at a preliminary stage and usually hasn't been scrutinized by experts in the field. Also, conference abstracts rarely provide full details about methods, making it difficult to judge how well the research was conducted. For these reasons, articles based on conference abstracts should be no cause for alarm.

Was the research in humans?

Quite often, the "miracle cure" in the headline turns out to have only been tested on cells in the laboratory or on animals. These stories are regularly accompanied by pictures of humans, which creates the illusion that the miracle cure came from human studies. Studies in cells and animals are crucial first steps

and should not be undervalued. However, many drugs that show promising results in cells in laboratories don't work in animals and many drugs that show promising results in animals don't work in humans. If you read a headline about a drug or food "curing" rats, there is a chance it might cure humans in the future, but unfortunately a larger chance that it won't. So there is no need to start eating large amounts of the "wonder food" featured in the article.

How many people did the research study include?

In general, the larger a study the more you can trust its results. Small studies may miss important differences because they lack statistical "power" and are also more susceptible to finding things (including things that are wrong) purely by chance.

You can visualize this by thinking about tossing a coin. We know that if we toss a coin the chance of getting a head is the same as that of getting a tail – 50/50. However, if we didn't know this and we tossed a coin four times and got three heads and one tail, we might conclude that getting heads was more likely than tails. But this chance finding would be wrong. If we tossed the coin 500 times – i.e. gave the experiment more "power" – we'd be more likely to get an even number of heads and tails, giving us a better idea of the true odds. When it comes to sample sizes, bigger is usually better.

Did the study have a control group?

There are many different types of studies appropriate for answering different types of questions. If the question being asked is about whether a treatment or exposure has an effect or not, then the study needs to have a control group. A control group allows the researchers to compare what happens to people who have the treatment/exposure with what happens to people who don't. If the study doesn't have a control group, then it's difficult to attribute results to the treatment with any level of certainty.

Also, it's important that the control group is as similar to the treated/exposed group as possible. The best way to achieve this is to randomly assign some people to be in the treated/exposed group and some people to be in the control group. This is what happens in a randomized controlled trial (RCT) and is why RCT's are considered the "gold standard" for testing the effects of treatments and exposures. So when reading about a drug, food or treatment that is supposed to have an effect, you want to look for evidence of a control group, and ideally, evidence that the study was an RCT.

HOW TO READ HEALTH NEWS (continued)

Did the study actually assess what's in the headline?

This one is a bit tricky to explain without going into a lot of detail about things called proxy outcomes. Instead, bear in mind this key point: the research needs to have examined what is being talked about in the headline and article. (Somewhat alarmingly, this isn't always the case).

For example, you might read a headline that claims, "Tomatoes reduce the risk of heart attacks". What you need to look for is evidence that the study actually looked at heart attacks. You might instead see that the study found that tomatoes reduce blood pressure. This means that someone has extrapolated that tomatoes must also have some impact on heart attacks, as high blood pressure is a risk factor for heart attacks. Sometimes these extrapolations will prove to be true, but other times they won't. Therefore if a news story is focusing on a health outcome that was not examined by the research, treat it with a pinch of salt.

Who paid for and conducted the study?

This is a somewhat cynical point, but one that's worth making. The majority of trials today are funded by manufacturers of the product being tested – be it a drug, vitamin cream or foodstuff. This means they have a vested interest in the results of the trial, which can potentially affect what the researchers find and report in all sorts of conscious and unconscious ways. This is not to say that all manufacturer-sponsored trials are unreliable. Many are very good. However, it's worth seeing who funded the study to sniff out a potential conflict of interest.

Should you "shoot the messenger"?

Overblown claims might not necessarily be down to the news reporting itself. Although journalists can sometimes misinterpret a piece of research, at other times the researchers (or other interested parties) over-extrapolate, making claims their research doesn't support. These claims are then repeated by the journalists. Given that erroneous claims can come from a variety of places, don't automatically assume they come from the journalist. Instead, use the questions above to figure out for yourself what you're going to believe and what you're not.

Behind The Headlines on NHS Choices

Source: Headlines / Neurological Foundation of NZ Volume 87 / Autumn 2010

THINK ABOUT YOUR THOUGHTS

The thoughts that circulate in your mind dictate how you feel. Let's say you are thinking about things that you love and enjoy, then you're going to feel happy. On the other hand if you are worrying about how you'll pay the bills on time you'll most likely feel anxious or depressed. How you feel in turn influences the decisions and choices that you make.

The cycle goes like this:



What you think about influences how you'll feel, and how you feel in turn influences all of the decisions, choices and actions that you make.

The good news is that you don't have to be a victim of your thoughts – you have the power to choose what thoughts circulate in your mind. It's only natural that you'll experience negative or fearful thoughts at times, we all do. Your power lies in the choices that you make. You can allow your mind to dwell on whatever pops into your consciousness. Or, you can choose to cancel worrying or fearful thoughts as soon as you become aware of them and replace them with thoughts that will help you create the life you really want.

Source: Love The Life You Live (Anne Hartley)

FOR SALE

Fisher & Paykel Voyager scooter. My mum has had to move into a nursing home/hospital due to ill health and is no longer able to use her scooter. I would keep it for myself but as yet my MS has not got to the point of needing it (I hope to keep moving for as long as possible).



It is about 12 years old and in good running order, has passed a 'warrant of fitness' service, so is good to go for 6 months before needing another service. It has just had 2 new batteries installed and 2 new inner tubes for the wheels. The tyres have some cracks in them but do not affect the wheels as they have inner tubes. Comes with basket and recharging lead. \$800 ono. Contact Noel or Shirley, (09) 294 6086 or 021 124 8672 email abbots@slingshot.co.nz

STANFORD UNIVERSITY HALTS CCSVI TREATMENTS AFTER TWO SERIOUS INCIDENTS

Researchers at Stanford University have halted treatments for chronic cerebrospinal venous insufficiency (CCSVI) according February's edition of the journal Annals of Neurology.

The decision came after two people experienced serious side effects following stenting of the jugular veins, a procedure thought to correct CCSVI. One patient died from a brain haemorrhage following the procedure in August and another required emergency open heart surgery in November after a jugular vein stent dislodged into the right ventricle of the heart.

Dr Jeffrey Dunn, associate director of Stanford's MS centre, called on other neurologists to speak out about the potential "dangers" of the unproven procedure: "If I can do anything to protect MS patients from the potentially devastating effects of false hopes or the risks of invasive and unproven treatment, I am happy to do so".

The theory that CCSVI may play a role in causing MS was developed by Italian Cardiovascular Surgeon Dr Paolo Zamboni and has resulted in much debate and controversy. It has also sparked interest in many of the 2.5 million people with MS world-wide as a potential cause of MS.

Dr John Richert, executive vice president for research and clinical programs at the National Multiple Sclerosis Society in the USA said, "When dealing with a disease like MS, where we don't know the cause or have many therapeutic options, it's important to think outside the box. Dr Zamboni is doing this, but his techniques need to be confirmed."

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@msaki.org.nz

He went on to add, "All of the evidence today is preliminary. There is not even enough evidence to say that obstruction of veins might be a factor in MS, or to determine when this obstruction may occur in the course of disease."

MS Societies around the world have emphasised that new research studies will be pivotal in determining the link between CCSVI and MS before surgical procedures should be made available to treat CCSVI.

Researchers in Buffalo NY are investigating the prevalence of CCSVI in people with MS. Dr Robert Zivadinov, Director of the Buffalo Neuroimaging Analysis Centre and principle investigator of the Buffalo says: "If we can prove our hypothesis, that cerebrospinal venous insufficiency is the underlying cause of MS, it's going to change the face of how we understand MS", but he added that media coverage of CCSVI so far has been premature and "unrealistic".

Source: www.mstrust.org.uk/news

OBITUARY

It is with great sadness that we mark the passing of MICHAEL JOHN MCCOOL, who died suddenly on 24th March at North Shore Hospital after a short illness.

Living with Multiple Sclerosis, Michael was a life member of MS Auckland Region and had served on the committee of North Shore MS Society where he was President for a number of years. During this time he was their national councilor to MS New Zealand and became a board member for the National MS Society.

Michael had been a supporter of disAbility Information North Shore, serving on committee for a number of years. His knowledge of the disability sector was extensive and invaluable in this role.

Always a fighter for disabled rights, Michael was a dedicated supporter of DPA on the North Shore. He was their President for a number of years frequently traveling the country as their representative.

A term as Properties Manager for the Philosophical Society and Master at a Masonic Lodge would seem to be enough for the average person, but Michael found time to study at Massey University Albany first achieving a Masters Degree and last year a PhD in Social Anthropology.

Those of us who have worked alongside Michael and value his friendship will miss his cheerful presence.

David Ashton

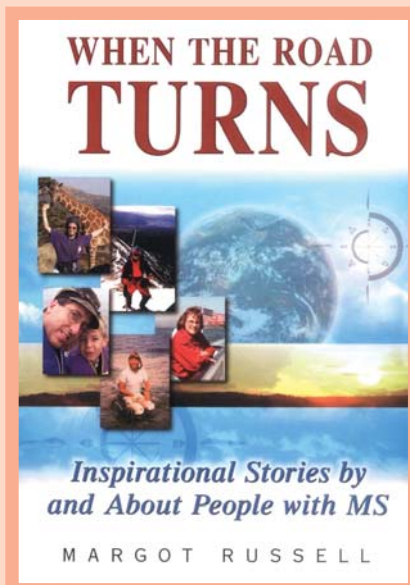
BOOK REVIEW

WHEN THE ROAD TURNS: INSPIRATIONAL STORIES ABOUT PEOPLE WITH MS

Margot Russell

When the Road Turns is a collection of inspiring stories written by people with Multiple Sclerosis. It focuses on 18 people with MS, who describe their journeys from diagnosis to acceptance and in doing so, talk about their concerns, frustrations, anger and, ultimately, acceptance. For example, Dave Perez, a divorced father, who single-handedly cares for his three children, describes how he overcame his sense of despair while dealing with MS by focusing on living for his kids. Inbal Tsur, an Israeli artist, writes about how she has learned to manipulate a paintbrush with her mouth after losing the use of her arms. Others include renowned oceanographer Richard Radtke, who becomes the first disabled man to reach the South Pole and a woman who is now enjoying life as a mother to a new baby despite doctors' advice not to further risk her health by becoming pregnant. Each of these people dealt with these challenges after they were told they had multiple sclerosis, proof that life doesn't end with an MS diagnosis.

Review by Rachael Turner-Ford



RECIPE CORNER

COURGETTE SALAD WITH SULTANAS AND PINE NUTS

This tasty vegetable salad from Tamasin Day Lewis couldn't be simpler to make. Serves: 4

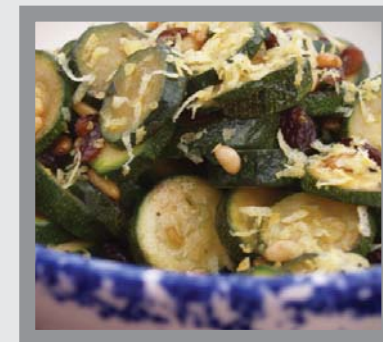
Ingredients

- 2 tbsp extra virgin olive oil
- 3 Courgettes, thickly sliced
- 1 garlic clove, sliced
- juice of 1/2 lemon
- small handful of sultanas
- small handful of Pine kernels
- salt and fresh ground black pepper

Method

1. Heat the olive oil in a frying pan. Add the courgettes in a single layer and fry over medium-high heat for about 2 minutes until the underside is lightly flecked with brown.
2. Turn carefully with tongs, then add the garlic and fry for another minute, taking care not to let the garlic burn.
3. Pour over the lemon juice, add the sultanas and pine nuts and season with salt and pepper. Lower the heat and fry for another 5 minutes until the courgettes are just tender.
4. Serve warm or at room temperature.

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

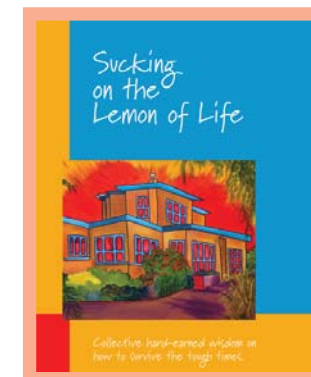


SUCKING ON THE LEMON OF LIFE

Sucking on the Lemon of Life is a book produced by residents of The Beacon, a Presbyterian Support-facilitated community initiative that offers respite and day activities for younger people with chronic, degenerative neurological conditions such as multiple sclerosis, motor neurone disease, and Parkinsons.

The book is written by some of the residents who have had to deal with disease and disability, experiencing pain through their journeys of life. It is their collective hard-earned wisdom on how to survive the tough times. This is a book for everyone, not just those with neurological conditions.

The book is only \$25 + \$4 postage and can be ordered by visiting <http://thebeacon.org.nz/sucking-on-the-lemon-of-life-book.html>



MS GROUPS

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

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).

NORTH SHORE

NORTH SHORE CAFÉ GROUP

Last Saturday of each month, 12.30pm

Kings Garden Café, Kings Plant Barn, Porana Rd, Glenfield. Contact Christine Ball for more information on (09) 444 6945 or 021 071 6752 after 4pm.

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.

MAIRANGI BAY WATER-WALKING

Wednesdays 10.30am to 11.30am

At the Millennium Sports Institute with a Physiotherapist, Margo Angland.

MAYFIELD COFFEE MORNING

1st Thursday of each month, 10.30am

At the Mayfield Centre, Glenfield. The next meetings are 6th May and 3rd June. All are welcome.

HIBISCUS COAST BUDDIES

3rd Tuesday of each month, 10.30am

At the Pohutakawa Room in the Whangaparaoa Library. All welcome.

AUT PHYSIOTHERAPY MS CLASS

Classes start on Monday 8th February at AUT, Akoranga Campus, Northcote. Contact the clinic for details on (09) 921 9161.

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

Thursdays 9.00am until May

Waitakere Shaolin Kempo & Tai Chi School runs a free Tai Chi group at the Trusts Stadium in Henderson. It is open to all members of the MS society to give it a try. More classes may be available after May if there is enough interest.

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 Ann Keith, Ph (09) 534 3845 (10am to 4pm Mon, Tues, Thurs & Fri).

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.



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

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 Jake at the office on (09) 845 5921.