

multiple news

The bi-monthly newsletter from Multiple Sclerosis Auckland

Welcome to Patron Dr Jennifer Pereira



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Dr. J. Pereira

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A few words from the GM...

I was very lucky to attend a course in Melbourne called 'The Heartsmart NPO Masterclass' run by Hailey Cavill. It was nothing short of brilliant. I loved every moment of the full on three days. We were learning a successful ten step process of engaging long term Corporate Partnerships, where we see the Society needing to go, rather than relying on grant funding. The course was extremely intense and after I returned, I really hit a wall.

After the course, I spent a day at the MS Melbourne Office and 'wow' that was something to behold. It is massive, they own their own two story building and rent another one level building alongside them. They have their own café, resource centre, large library and a call centre where a dedicated team of four people receive phone calls and answer questions relating to MS. This call centre operates 24 hours a day and 7 days a week and receives approximately 700 calls per month. MS Melbourne don't run any courses, (e.g. Hydrotherapy, Yoga,) they purely educate people about MS. Melbourne's office covers Victoria, NSW and ACT and Victoria on its own looks after 5,500 people with MS. The three states look after 15,500 in total. What I found interesting when talking to one of the managers of the Society was that they do not promote Professor Jelinek's programme and they have very few people that follow it, although she said, those that do follow it are very vocal. Amazing to hear when George Jelinek is on their doorstep! They've also never heard of Dr. Terry Wahls. MS Melbourne has a huge research operation and have a yearly campaign called "Kiss Goodbye to MS" which raises millions for Research. MS Melbourne have had the drug Tysabri, funded since 2008. Please see in the Members' Stories section later in this publication what we are doing to get Pharmac to fund Tysabri here in New Zealand. Australia is well ahead of New Zealand on so many levels.

For those of you who attended our recent AGM/Research Day, you certainly had access to top speakers on the subject of Multiple Sclerosis. In the Research section later in this publication, you will read a summarised version of what the speakers addressed. The venue was ideal and had plenty of space for wheelchairs. The catering was great although the caterer did put dressing on the salad as opposed to on the side – never mind we will get it right next year. We took the opportunity to welcome Dr. Jennifer Pereira as another one of our Patrons. Jennifer joins Dr. Ernie Willoughby, so the Society is in very good hands.

As you will be aware we are holding a major fundraising event on Sunday 27th July. You may not be able to attend, however you may have family members or friends who can, so please let them see the Life Buoy for MS advertisement later in this edition. We are proudly partnered by Fidelity Life (Insurance), Harcourts – Cooper & Co and Man O'War Vineyard. This day promises to be amazing and we are going to make it an annual event. We are delighted that our hosts are Ambassadors John and Lorraine Street, our President Neil Woodhams, MC is Peter Montgomery, guest speaker is Graeme Sinclair (person with MS) and special guest Rick Dodson (person with MS). We have a great line up of treats, so book your seat early.

Lastly I am going to share my Mother's Day with you. I hope all the mothers reading this were made to feel special, I certainly was. My morning started off with my husband getting me out of the house, so our four children could get to work. I was brought back home at 1.00pm to an amazing formal dining table set with a bottle of my favourite French champagne on ice. Each of our four children had prepared one course, so we enjoyed a degustation lunch. They also gave me a fabulous top as a gift which was handmade by our eldest son's girlfriend's mother (she is extremely talented). After lunch we all played "Ellen DeGeneres' Heads Up Game" and we all had such a great laugh. I loved the time spent with my family.



THÉRÈSE RUSSEL
GENERAL MANAGER



ms.
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AUCKLAND

Notice Board

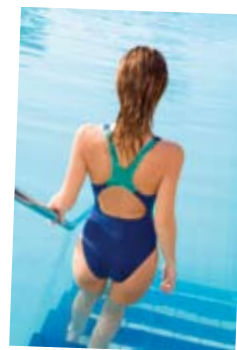
DREAMs

Do you have a reasonable "Dream"? Tell us about it and we will see if we can make it happen. No promises and don't make it huge. Email therese@msakl.org.nz or phone 845 5921.

Honorary Life Members

Always appreciated
– Never forgotten
David Ashton
Jo Smith
Doug Threthowen
Ken Wadham
Judy Wear
Tina French
Barbara Broome
Nancy Caughie
Judith and Rob Linton
Brian Stevens
Bruce Cameron
Ken Hall

Saturday Hydrotherapy
Classes are held at Diocesan School in Epsom. Concession cards cost \$50.00 (\$5 per session). There are limited spaces so first in first served!! You asked for it and we have delivered - don't miss out.



SAVE THE DATE 27TH JULY

A huge fundraiser for MS Auckland at the Royal New Zealand Yacht Squadron. Get a table of 10 friends together and join us for a lunch with each course sponsored by some of New Zealand's finest wines. More details to follow.



WE NEED YOU!!!

We are now looking for volunteers for our Street Appeal Friday 6 & Saturday 7 September. Call Pam to register your interest. Or email streetappeal@msakl.org.nz

HELL



We are excited to be working with HELL again this year during our Street Appeal. HELL will donate money to MS Auckland for every pizza they sell during our Awareness Week – 31st August to 6th September.

Calendar

Important dates to remember...

7th June

Wellness Workshop

10.00am - 12.30pm

Making Change Stick

Kelly Davis-Martin

18th June

Mix n Mingle

Sale St Bar

6.00pm - 8.30pm

21st June

Members Lunch

Swanson RSA

12.00pm - 2.30pm

12th July

Wellness Workshop

10.00am - 12.30pm

Yoga & Relaxation

Manada Carrigan

27th July

Life Buoy for MS

RNZYS

12.00pm - 4.00pm

9th August

Wellness Workshop

10.00am - 12.30pm

Continence
Janet Thackray

From the field...

Our Field Workers



Diane Hampton,
North Shore



Carol Andrews,
Central



Georga Forgac,
West



Dianne Bartlett,
South

Neuro Rehab Results is a private rehabilitation clinic based at Northcote Central on the Shore which is accessible for people from some areas of Central, the North Shore, Hobsonville, Whenuapai, Kumeu, Riverhead and Silverdale areas.

They currently offer a Balance-Fit class that is open to PwMS.

Balance-Fit Class – these classes are for people who want to improve their balance and reduce the risk of falls. It costs \$80 for 6 weekly sessions on Fridays from 11am to midday. This money is paid up front and attendees come in for a free ½ hour assessment prior to starting the group classes. After 6 weeks there is a break of 1 to 2 weeks and people can then start another lot of 6 sessions. The exercises are circuit based and comprise of 13 stations where people spend 3 minutes at each station. Each station has 3 options from easy to hard, depending on ability. The first group session is spent learning the circuit. Volunteer physiotherapy students from AUT are there to assist people when required.

Physiotherapist and Director Suzie Mudge says they have people with a wide range of abilities.

Movement Class – Currently Neuro Rehab Results run classes called Move! for people with Parkinson's Disease. If there is enough interest from PwMS they would look at trialling a similar class for us. These classes would comprise of exercises involving upper body and lower body. Again, the sessions would cost \$80 for 6 sessions and individual assessment paid up front.

Suitable days would be Tuesdays, Wednesdays or Thursdays and times such as 11am–12, 12–1 or 1–2pm would be best. If you are interested in a group being started for PwMS please contact your Field Worker. If there is enough response Neuro Rehab Results will set up a group for PwMS.

People can request a receipt to qualify for their Disability Allowance if required.

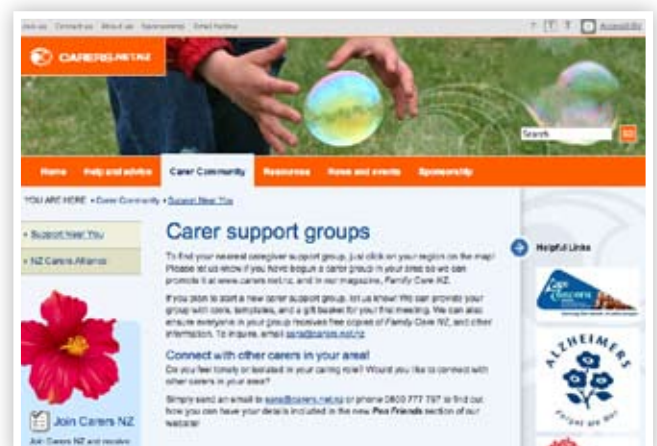
Cheers from Diane, Carol, Georga and Dianne!

Carers' Corner

A useful website for Advance Care Planning
www.advancedcareplanning.org.nz



A useful website for Carer Support Groups
http://www.carers.net.nz/carers_community/support_near_you



Welcome to Patron Dr Jennifer Pereira

We are very fortunate to have two top Neurologists as MS Auckland's Patrons, Dr. Ernie Willoughby and Dr. Jennifer Pereira. Many Members were lucky enough to be at our recent Research Day where Dr. Pereira was one of our presenters.

Dr. Jennifer Pereira works as a neurologist at Auckland City Hospital. Jennifer is also employed by the University of Auckland where she works as a Senior Lecturer in Neurology.

She has a special interest in immune therapies for the treatment of Multiple Sclerosis. Jennifer completed her neurology training in Auckland and then with the Therapeutic Immunology Group in the Department of Clinical Neurosciences in Cambridge, UK.



From the MS Nurses



It feels like we are into serious winter weather this week! A pertinent reminder for any of you who are undecided on getting the flu jab this year.

Auckland Hospital is readying itself, as it does every year for the significant increase in inpatients and pressure on beds that is caused by flu.

As you are no doubt aware the flu jab will not protect you from every flu out there. The most virulent strains are predicted and targeted with the jab.

We would strongly urge you to have the flu jab. If you have MS you can reasonably expect that catching the flu will hit you that bit harder than someone who does not have MS. The fever that accompanies it may aggravate your previous symptoms or make fatigue levels that bit more difficult to manage. So if you're wavering or indecisive go for it!

On a different subject. We have had a number of queries following the 'Sunday' Current Event story on Autologous Hematopoietic Stem Cell Transplant (HSCT) treatment. If this is something you would like to learn more about this link to the MS Society Australia will give you further details

<http://www.msaustralia.org.au/news/ms-australia-statement-autologous-hematopoietic-stem-cell-transplant-hsct-treatment>

Many thanks,
Fiona and Nazila

Donations Regular Monthly Donors

Thank you to all the wonderful people that give a monthly donation to the Society. This is a huge help to us, as it allows us to plan ahead knowing we have regular funds coming in. Each month we have a monthly draw and the winner receives 20% of the total monies deposited, so far this amounts to \$64.00.

Our objective is to increase our regular donors list and our monthly earnings, so if you are keen to be a donor, please call the office. It is a great way for your friends and family to support your Society and the donation can be \$10.00 or more (the cost of three cups of coffee).

Our May winner was Wendy Tizard, who very kindly donated it back to the Society.

Our June winner, Sandra Magill, was delighted to hear of her win.

Please phone Kirsty on 09 845 5921 to register as a Regular Monthly donor.

Rope Neuro Rehabilitation

Hello everyone, I trust you had enjoyable Easter and Anzac weekends! I went to my first dawn parade at the Auckland Domain, although an early start, definitely worth it. With the weather cooling down now, some of you might find it a little bit easier to start completing some exercises. Remember if you suffer from fatigue, start small and take the time to build up your tolerance bit by bit. If you want to work on your fitness and strength goals in a supervised setting, hydrotherapy is perfect, as it is guided by one of our physiotherapists who can give you individual information as to what is appropriate to you – I strongly suggest that you try a class.

I have had the pleasure of taking the Saturday hydrotherapy group over the past few weeks – what a fantastic facility. It has been great to meet new faces, those who can't attend during the week due to work commitments, and of course the familiar faces too who are adding another pool to their exercise regime! This pool is great as the floor is adjustable. This means that we do half our exercises with the hydro belt and half weight bearing at the shallow end, giving you access to both types of hydrotherapy exercises. Feel free to come and trial the Saturday hydrotherapy class to see if it suits you! Please note, that if you require a hoist to get in and out of the pool, this class may not be suitable.

Diocesan School for Girls, 10.00am – 11.00am Saturdays

We are in the middle of our current Minimise Fatigue, Maximise Life group currently and I wanted to share with you a couple of key concepts that we have already covered.

1) Identifying what type of fatigue you suffer from, physical or cognitive, as this will impact what type of rests are suitable for you.



Physical Fatigue: Also described as motor fatigue; weakness worsens the more the muscles are used. Speech can become slurred and it can become quite a process even managing to put one foot in front of the other.

Type of rest: Reading, watching TV, puzzles

Cognitive Fatigue: The ability to think or follow a thought plan reduces. It becomes tiresome thinking about the most simple of tasks. There can be an overwhelming desire to rest if not sleep. Concentration, memory recall and word finding can also become impaired.

Type of Rest: Meditation, breathing training, sleeping

2) Preventative resting: This concept has been hugely successful in our current group. This is all about resting before you get fatigued. The best way to start implementing preventative resting is to start planning your days and scheduling it in. It can also be taking 10 minutes to rest even when you are feeling good. This can be quite a mind shift change, but can also be very effective.

If you struggle from fatigue, Rope Neuro Rehab can help, give us a call to discuss your situation and we can book in a fatigue management education session to help you.

Stephanie and the Rope Neuro Rehab Team.

Recipe Creamy (Dairy Free) Fish Chowder

Serves 4

Ingredients

- 1 large head cauliflower, coarsely chopped (800g)
- 2 cups water
- 2 cups fish stock
- 227g mushrooms, sliced
- 1 small onion, chopped
- ½ orange pepper, finely chopped
- ½ tsp salt
- ¾ tsp black pepper
- 450g prawns or shrimp or other shellfish, thawed
- 400 g fresh firm white fish diced.
- A pinch of nutmeg.
- Lime zest and juice to garnish

Method

1. Add cauliflower, water, fish stock to a large stockpot. Bring to a boil, lower heat, cover and cook until the cauliflower is really soft and tender, about 5-7 minutes.
2. Meanwhile, cook the mushrooms in a large skillet over medium-high heat until golden on both sides. Lower the heat, add onion, orange peppers, salt and pepper and continue cooking until fragrant and onions start to turn translucent, about 2-3 minutes. Reserve.
3. Ladle the cauliflower mixture into your blender and process on high speed until super smooth and silky in consistency. You might have to work in several batches
4. Return that soup base to the stockpot and add the nutmeg, shrimp/ prawns/ shellfish and fish plus reserved veges.
5. Bring back to a boil, reduce heat and simmer until the seafood is cooked, making sure to remove any shellfish that has failed to open... about 4-5 minutes.
6. Serve immediately and hit with a splash of lime juice. Garnish with lime zest.



Sandra Perry Dip.Nutrition
Nutritionist



360^o nutrition

55 Bushlands Park Drive Albany 0632

p: 09 415 2676 m: 021 1546999 e: nutrition360@xtra.co.nz

7 June

Making Change Stick

Speaker: Kelly Davis-Martin

Are you ready to see change? How to identify what you want, why you want it and how to take steps towards achieving your dreams.

This engaging talk will be a show-and-tell experience for the audience that will combine research, best practice, humor, and fun. The goal of this presentation is to share the latest on how to actually facilitate change by exploring how to know what you want, why you want it and what to do about it. We will explore the science and neurology behind behavior change and uncover the truth about our old techniques and the new approach of coaching people to change.



Mikki Williden

FEEDBACK

"Went over what I know, but reinforced what I should be doing".

"Although it was contradictory to my current diet, it was very interesting to hear a different perspective on nutrition and has questioned some of my beliefs which I will discuss with George Jelinek on his website".

"Helped explain some things I've read about in "Wahl's Protocol". However, raises some significant questions and contradictions with George Jelinek's research on fats. Much is similar though".

"Her depth of knowledge was inspiring".

12 July

Exercise – Yoga and Relaxation

Speaker: Mananda Carrigan

This relaxing and rejuvenating workshop will incorporate simple, gentle yoga exercises, breathing and relaxation techniques designed to release tension, relieve stress, bring peace of mind and promote better health and wellness. Letting go of tension and stress helps to reduce pain and encourage greater mobility. Our energy levels are heightened. The gentle depth of Transformation Hatha Yoga and relaxation techniques increases our sense of wellbeing and inner calm. MS Auckland will supply yoga mats.



Catherine Newton

FEEDBACK

"Made me face up to reality and make steps towards making some positive changes".

"Reminder that there is power in unconscious thought".

"She was wonderful and I learnt lots. It has given me heaps of things to do at home and expand on what we did during the session".

"Catherine was inspirational, motivational and educational – look forward to listening to her next year".

9 August Continence

Speaker: Janet Thackray
– Continence Nurse

Janet is a Community Nurse Specialist working in central Auckland with over 2,000 patients on her books. Her role is to promote continence of bowel and bladder by using various conservative measures such as bladder retraining and lifestyle changes. Janet will focus on the practical management of incontinence and will bring along the products and equipment to help with this.



Events

Brain Day Expo



Managing the MS stand at Brain Day Expo this year are South Field Worker Dianne Bartlett, and Committee Members Michael Cole and Louise Reed (in red).

Member Ken Hall is honoured



Mr Ken Hall graciously accepted the Honorary Life Member award on behalf of his wife and all caregivers from Neil Woodhams (President Auckland) at the AGM. Ken noted that he is almost a foundation member of the Society having been associated for 47 years of the Society's 49 years of existence. Ken then paraphrased John F. Kennedy, saying "Don't ask what the Society can do for you, rather ask what you can do for the Society."

BOOKINGS ESSENTIAL



MS MEMBER'S WEST WINTER LUNCH

Saturday 21 June 12.00 - 2.30 pm

**SPECIAL GUEST SPEAKER
WOLFGANG WOLF**

Friends and family welcome

Members - \$18

Non Members - \$25

Raffle tickets for sale: 3 for - \$5

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663 Swanson Road, Swanson**

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or email: info@msakl.org.nz to book

<http://www.captiveaudience.co.nz/speakers/wolfgang-wolf>

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SUNDAY 27TH JULY, 2014, 12–4PM

COMMENCING WITH MAN O' WAR TUULIA METHODE TRADITIONELLE AND CANAPÉS
FOLLOWED BY A THREE COURSE MEAL

\$1,800 FOR A TABLE OF TEN OR \$200 PER TICKET (INCLUDES WINES)

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MC – PETER MONTGOMERY

GRAEME SINCLAIR - GUEST SPEAKER



TELEVISION PERSONALITY, AUTHOR, PUBLIC SPEAKER, A MEMBER OF THE NZ ORDER OF MERIT FOR SERVICES TO TELEVISION, FISHING GURU AND TV3 'GONE FISHIN' PRESENTER. GRAEME IS A PERSON WITH MS.



RICK DODSON - GUEST APPEARANCE

MULTIPLE OK DINGY WORLD CHAMPION, OLYMPIC GAMES CONTESTANT, HALBERG AWARDS WINNER, ADMIRALS CUP WINNER, WORLD ONE TON CUP WINNER, AMERICA'S CUP WINNER IN 1995 AND ALSO 2000 AND A PERSON WITH MS.



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Events

MS Good Sorts kicks off in a sea of orange and tea cups!

May is International Multiple Sclerosis month and Members from MS Auckland are doing their bit to increase awareness of MS within their own communities by hosting a tea party.

MS Good Sort, Judith Herbert hosted the first of 13 booked tea parties at her home in Albany. Making the most of Mother's Day, Judith invited mothers and daughters to attend her party on the Sunday morning. Around 30 friends chatted over the tea cups and enjoyed delicious homemade goodies for morning tea. Judith had decorated her home with balloons, serviettes and plastic plates all in the MS orange all supplemented by Judith's bright orange MS apron!

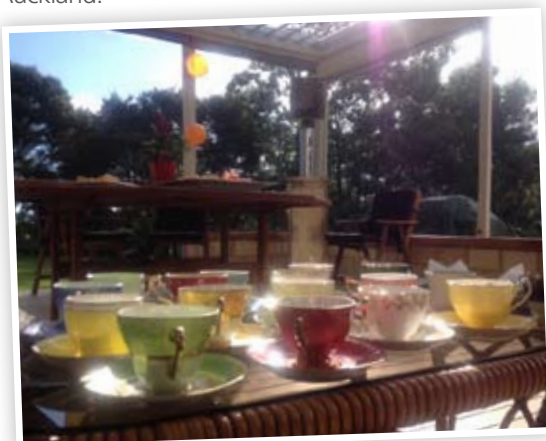
Having organised a few raffle items herself, Jude had a collection box on hand for donations. The morning was a great success with Judith raising \$860 for the Society.

Committee Secretary Fran Watts hosted the next party and writes "Orange balloons were dotted all around the house and letterbox, and the invites were sent. A friend had organised a group of people to bring along afternoon tea. As I sat in the house alone an hour before the tea was due to start I wondered how many people would come and if there would be enough food. Within half an hour there were more than 20 smiling faces, all donating enthusiastically whilst enjoying delicious food and fellowship.

"As the minutes rolled by, more and more friends arrived and the final count was 37! Many ladies asked about Multiple Sclerosis and were interested in the research and the good work the Society is doing. All in all, a very successful afternoon with lots of fun and laughter to be had!"

At first tally Fran thought she had raised around \$500 however on the final count she had raised over \$1,000!!

If you would like to be a MS Good Sort and host a party, or if you know of any businesses who might like to donate raffle items please call Pam in the Office to for more information. This is an ideal way of raising awareness and funds for MS Auckland.



EVERY MORNING
YOU HAVE TWO
CHOICES: CONTINUE
TO SLEEP WITH
YOUR DREAMS,
OR WAKE UP AND
CHASE THEM.

HOW DO WE STAY IN OUR FAMILY HOME?



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SALE

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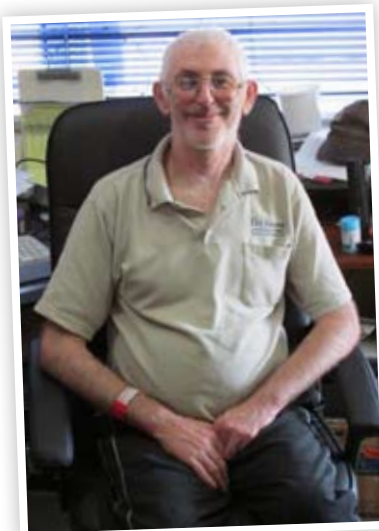
DREAMs

Tim's Treat!

Tim's DREAM was to receive a really solid office chair with arms for resting on and it had to have wheels. We are delighted to have delivered Tim the chair of his DREAMs, thanks to Warehouse Stationery, Wairau Park. They were thrilled to help Tim out and loved receiving a call of thanks from Tim himself.

Tim says "I love my chair, I feel on top of the world. Finally I feel like the boss!"

Don't forget if you have a DREAM tell your Field Worker about it.



Update on Jody



We thought we would give you an update on Jody who had her DREAM come true thanks to a free Membership from Jetts. They even introduced her to a personal trainer, Ati Keepa, who is donating his time for free. Here is what Ati has to say about Jody... "I have been training Jody for four weeks now and she is going great. Our first day of training consisted of tests to get an idea of what Jody was capable of doing. We started with a gentle walk on the treadmill, after 20 minutes her leg gave way and she had to stop. We tried the rower, which Jody seemed to be okay and I gave her a target of achieving 1500m twice a week. As there was so much of Jody's lifestyle that she needed to change, we decided that a 12 week challenge would bring a bit more structure and guidance as she set about on this new journey. The purpose of the challenge was to ensure that Jody changed her eating habits, set regular training times and also kept in touch with me on a regular basis so we could ensure that she wasn't pushing passed her limitations.

"As her trainer, I am happy to report that in four weeks Jody has made phenomenal changes. Not only does she eat healthier, but she trains six times a week at the gym and if she can't make it to the club, she goes for a walk.

"I have started her on a programme that is specifically designed to strengthen her leg and by the second week we both noticed a huge improvement. Jody has even managed a 3 hour mountain walk. However, what is more remarkable, is that in week 4, Jody is able to jog on the treadmill. A massive change from week one where even walking was difficult.

"Jody is doing an amazing job and is a great lady with a great smile! Jody has already lost 5.5kgs and is pushing to lose more, however our biggest goal is to ensure that those everyday tasks become a little easier. Jody is feeling amazing and enjoys training now, she pushes past the pain and gives it everything she has. I am so proud to be her trainer and to see her change as she reaches the little milestones on her journey. Watch this space as we have 8 weeks left to go on the challenge and there is no stopping Jody!"

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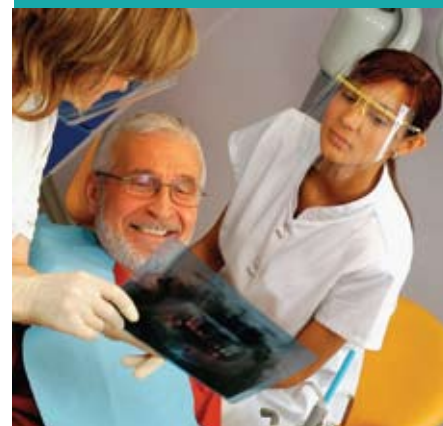
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Our Elder Dental Care Team

Our friendly team is looking forward to helping you.

Dr Clive Ross

CNZM BDS (NZ), FDSRCS (Eng), FRACDS, FICD, FADI

Clive is a part time Clinical Director of the ADHB Regional Oral Health Service, and a specialist in restorative dentistry with over 30 years in private practice.

Dr Guo Ling

BDS (Otago) DCLINdent (Special Needs Dentistry)

Guo holds a dental consultant position at Greenland and Middlemore Oral Health Units, and has a special interest in the oral health of older patients.

Lyn Jenkinson

Dental Practice manager

Lyn is an experienced dental practice manager with skills in chair-side dental assistance and oral health education, with an emphasis on understanding the needs of the older person.

Members' Stories

Tired of being labelled a drunk

A former America's Cup sailor is fed up with being refused alcohol because his illness makes him appear drunk.

Mairangi Bay father of two Rick Dodson, 54, says bar and liquor shop staff need to understand the symptoms of multiple sclerosis (MS) before making snap judgements.

"I went to a wine shop in Parnell the other week and asked for a six pack of beer because I was going to a friend's place for dinner.

"The guy behind the counter said, "No I can't serve you because you're drunk."

Mr Dodson says the staff member continued to refuse him a sale even after he explained that his slurred speech and unsteadiness on his feet were symptoms of MS.

"I showed him my MS card, but he said, "No I can't, I still think you're drunk."

MS Auckland, a support organisation for those with the condition, provides members with wallet-sized cards explaining the symptoms.

Slurred speech, shaky hands and affected balance are symptoms that have been causing problems when people with MS attempt to drive or purchase alcohol.

Others may experience fatigue, numbness, spasticity and bladder problems.

"Everyone with MS has this story. It's happened to me in bars as well," Mr Dodson says.

MS Auckland General Manager Thérèse Russel says no two people exhibit the same symptoms which makes it difficult for people to recognise the disease.

"To other people they are all signs that someone is drunk."

She says another member had her keys taken off her in the car park as she went to drive home.



Mr Dodson says he is frustrated with uneducated people denying him the freedoms he is entitled to.

"I respect them for doing the right thing and saying, 'Look, no, you're drunk', but as soon as I pull out the card that should be the end of it."

MS Auckland is now looking to produce a new identification card to prevent any further disputes.

"The issue we have is how do we make it more recognisable? Maybe something with a photo on it, our website, symptoms and a phone number to call?"

Mr Dodson says his team mate David Barnes, who also suffers from MS, does not drink but has still had to contend with ignorance from retail workers.

"Dave got stopped outside the supermarket, the police showed up in the car park after the checkout girl said something. "His daughter was with him at the time and said, 'No, it's OK, Dad's got MS'."

Both are members of the Kiwi Gold sailing crew, vying for a spot in the Rio de Janeiro 2016 Paralympics.

Ad Feedback

Mr Dodson was the Team NZ on-board strategist during both the 1995 and 2000 America's Cup victories.

He was diagnosed about 15 years ago but continued to sail with Team NZ in the early stages of the disease.

He has since undergone speech therapy and continues to live a full and active life.

Inspirational Thought

**"Watch your thoughts; they become words.
Watch your words; they become actions.
Watch your actions; they become habits.
Watch your habits; they become character.
Watch your character; it becomes your destiny".**
– Frank Outlaw

Read more at <http://www.beliefnet.com/Quotes/Inspiration/F/Frank-Outlaw/Watch-Your-Thoughts-They-Become-Words-Watch-You.aspx#OdK56mEqG1GGT7bo.99>

Dear Volunteer

As a Volunteer your role is unpaid,
Not because you are worthless
Because you are PRICELESS
Thank you so much for all you do.

Members' Stories

Warwick Russell

No, this gentleman is not a relation of mine (I am Thérèse Russel with one 'l'), however he is a very talented New Zealand artist and has MS. Warwick has very generously donated three of his masterpieces to our Fundraising Lunch in July, where two will be auctioned and one will be in a silent auction. We are extremely grateful to Warwick for this very generous contribution.

Warwick's Story

"As a student I had excelled in art classes, having been blessed with a natural talent for illustration. I pursued art at secondary school and followed up with evening classes. In 1960 I established a graphic art studio in Sydney and ran it for three years, during which time I was invited to join the 'Black & White Club' art group. This group had well-known illustrators and cartoonists such as Clem Seale, Tony Rafty and Eric Joliffe among its members.

"My OE took me to London and Europe and included a summer in the eastern Mediterranean sailing, sketching and painting. Then I moved on to the Caribbean and Florida. Arriving back in New Zealand in 1964, I started my own graphic studio but by 1998 computers had taken over so I decided to concentrate on the enjoyment of serious watercolour painting. I turned my woolshed into an excellent studio, which became the meeting



place for a small group of like-minded people who met weekly. We called ourselves 'The Woolshed Art Group'. Since then I have had some success in art exhibitions.

"The spontaneity of water colour gives the feeling of positive attitude to my work, with a freshness and strength of colour and with fast direct expression.

"With my yachting and farming background I am happy painting seascapes, landscapes and old buildings. I live in rural Whitford, South Auckland."

Warwick Russell is a member of the NZ Fellowship of Artists. He has won many awards at exhibitions including the Royal Easter. His paintings are in private collections in Australia, UK, USA and Europe.

In 1986 he was diagnosed with MS, swimming daily maintains his mobility, and his painting provides much satisfaction.

HAVE YOU PAID YOUR 2014 SUBSCRIPTION?

All those who attend the support and swimming groups please make sure you have paid your subs and are Members. Anyone who has our equipment on indefinite loan should also be Members. We must enforce our subscriptions as our Field Workers' time is in such huge demand that they can only attend to Members.

Have you heard of:
Knowledge is Power?

Well it's not:
Knowledge is POTENTIAL Power

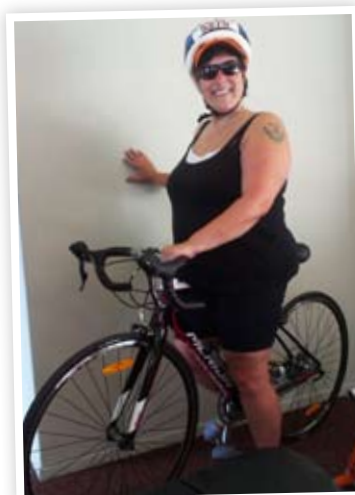
However:
APPLIED Knowledge is Power

HELL to the Rescue

When our Member, Bronie emailed me to ask if there was any chance of borrowing a bike to partake in 'Bike the Bridge' again this year, we couldn't help her, so we went to the National Marketing Manager Jason Buckley, at HELL. We asked if HELL would buy Bronie a bike and within one minute their email reply was "That's a no brainer, we'll do that". Not only did HELL buy Bronie a fantastic bike, but also a special bike stand that she can train indoors on. Bronie is in seventh heaven that she can ride in this fun event again and is looking to beat her time of last year. We will keep you posted with her success and training.



If you are interested in riding 'Bike the Bridge' this year please contact our office on 09 845 5921.



Members' Help Wanted

Welcome to the Patients Steering Group for MS Drugs

The group has been established to advocate for the public funding of MS drugs and has put together a project plan for the period up to September.

Neil Woodhams, President of MS Auckland, is leading the group with assistance of interested participants, now listed as 24 as at 20 May, who seek to have these treatments publicly funded.

Two weeks ago PHARMAC released the minutes of the February 2014 meeting of its Pharmaceutical Technical Advisory Committee recommending both Tysabri (Natalizumab) and Gilenya (Fingolimod), oral treatments, as the preferred primary and first line treatments for Relapsing-Remitting MS.

<http://www.pharmac.health.nz/assets/ptac-minutes-2014-02.pdf>

<http://www.pharmac.health.nz/assets/ptac-neurological-subcommittee-minutes-2013-09.pdf>

It has taken PTAC more than three years to agree to this decision, and despite the endorsement of these new MS drugs as the preferred first line treatment, it continue to require patients to try and typically fail a course of treatment that it no longer endorses PHARMAC as providing the best opportunity for MS patients.

PHARMAC has not yet to agreed to fund its own preferred first line treatments. To date there are only 13 privately funded patients receiving the treatment of Tysabri, including four who continue to receive the medication from a manufacturer's trial.

Since PHARMAC took over the MS drug funding in June 2013 it has refused all NPPA (Named Patient Pharmaceutical Assessment) funding applications submitted by MS patients' neurologists.

PHARMAC continues to refuse to provide or commit to a date to provide funding for its preferred first line treatments. The MS community are extremely concerned that the PHARMAC funded treatments (which are now not recommended as being as effective) actually increase risks and diminish the efficacy of the new MS drugs. It has been advised and well known through global research that these oral medications provide the best chance of success in limiting or preventing disability when given early, unlike current treatments which are only allowed to be prescribed when a level of disability is visible.

It is not acceptable to the MS community that PHARMAC fails to make time sensitive decisions and avoids making a public commitment to decision-making timeframes.



New Zealand has significantly lagged behind all other Western nations in the funding of Tysabri (Natalizumab) and Gilenya (Fingolimod) treatments. Australia approved

Tysabri funding in April 2008 with around 2000 patients currently receiving Tysabri treatment alone.

MS patients in New Zealand want and deserve an adequate standard of publicly funded treatment and more transparency from PHARMAC on how it determines and budgets for its funding priorities for MS medications and treatments.

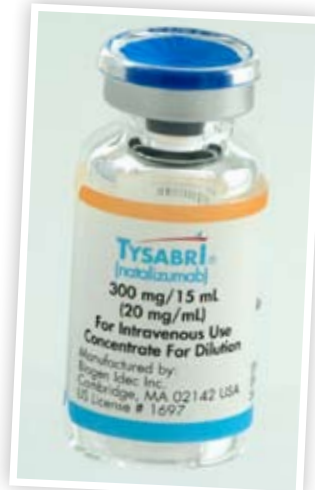
The MS community needs to hold both PHARMAC and our elected politicians to whom it reports to account. We seek your assistance to secure access to what is widely acknowledged as the best first line treatments for MS patients and to make the treatments available to all who would benefit from it. We are seeking a cross-party funding commitment from all major political parties prior to the general election.

In the first instance, please contact your Field Worker or the office to receive a full information pack so that you, your family and friends can be advised on the best process to get our Government to listen.

Yours sincerely,

Neil Woodhams
MSNZ Executive Committee Member

Malcolm Rickerby
MSNZ President



DISCLAIMER

MS Auckland advises that you do not simply rely on the information in these pages to imply any diagnosis or course of treatment for any particular individual. You should not rely on this information in place of a visit, call, consultation or the advice of a physician or other qualified healthcare provider. Content neither indicates nor reflects the views of MS Auckland. Any research, study, clinical trial, event, news or other item included in Multiple News is not intended to imply endorsement or approval of it by the Society. Although we have made a conscientious effort to provide high quality information, MS Auckland disclaims any implied guarantee about the accuracy, completeness, timeliness or relevance of any information.

Code of Health & Disability Services Consumers' Rights

Hi, I'm Sacha Dicks and I am one of three local advocates for the North Shore as part of the Nationwide Health and Disability Advocacy Service, provided free under the Health and Disability Act 1994.

Everyone using a health or disability service has the protection of the Code of Health & Disability Services Consumers' Rights. An independent Commissioner promotes and protects these rights under the Act. There are 48 advocates around New Zealand, eight of whom work in the Auckland area.

Advocates support consumers to speak up and resolve complaints about any health or disability provider, regardless of whether the provider is registered or qualified. Providers can include general practitioners, nurses, caregivers, physiotherapists, pharmacists, medical herbalists, acupuncturists, psychiatrists and dentists.

Our service also receives over 11,000 enquiries a year, about everything from tenancy problems, rights under the Mental Health Act, privacy matters, Work and Income New Zealand queries... and more! We aim to provide specific information if the issue is related to health or disability but also provide relevant contact details of services or agencies who can help if we can't.

One of our goals is promoting the rights of consumers under the Code and we do this by visiting health and disability services, attending community group meetings and by providing education sessions to both providers and consumers.

If you would like more information, speak to your Field Worker or contact the MS office 845 5921 and ask for a brochure to be sent to you.

HC HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Your Rights when receiving a Health or Disability Service

- **Respect**
You should be treated with respect. This includes respect for your culture, values and beliefs, as well as your right to personal privacy.
- **Fair Treatment**
No one should discriminate against you, pressure you into something you do not want or take advantage of you in any way.
- **Dignity and Independence**
Services should support you to live a dignified, independent life.
- **Proper Standards**
You have the right to be treated with care and skill, and to receive services that reflect your needs. All those involved in your care should work together for you.
- **Communication**
You have the right to be listened to, understood and receive information in whatever way you need. When it is necessary and practicable, an interpreter should be available.
- **Information**
You have the right to have your condition explained and to be told what your choices are. This includes how long you may have to wait, an estimate of any costs, and likely benefits and side effects. You can ask any questions to help you to be fully informed.
- **It's Your Decision**
It is up to you to decide. You can say no or change your mind at any time.
- **Support**
You have the right to have someone with you to give you support in most circumstances.
- **Teaching and Research**
All these rights also apply when taking part in teaching and research.
- **Complaints**
It is OK to complain – your complaints help improve service. It must be easy for you to make a complaint, and it should not have an adverse effect on the way you are treated.

If you need help, ask the person or organisation providing the service.
You can contact the local advocacy service on 0800 555 050 or the Health and Disability Commissioner on 0800 11 22 33 (TTY).

Why Multiple Sclerosis is more common in women

Washington, May 12 (ANI): A new study has found why so many more women than men get multiple sclerosis (MS).

According to the study by researchers at Washington University School of Medicine in St. Louis, females susceptible to MS produce higher levels of a blood vessel receptor protein, S1PR2, than males and that the protein is present at even higher levels in the brain areas that MS typically damages.

The researchers said that when they looked at the protein's function in mice, they found that it can determine whether immune cells cross blood vessels into the brain, which cause the inflammation that leads to MS.

The study also identified 20 genes that were active at different levels in vulnerable female brain regions, but the researchers don't know what 16 of these genes do.

The study was published in the Journal of Clinical Investigation. (ANI)





**Once-a-week AVONEX[®] treatment...
now made even easier.**

AVONEX is indicated for the treatment of relapsing forms of multiple sclerosis (MS)
to slow the progression of physical disability and decrease relapse rates.



Patient information: AVONEX[®] (solution for injection, in pre-filled pen) is a Prescription Medicine containing 30 micrograms of interferon beta-1a in 0.5mL of ready-to-use solution. Use strictly as directed. Consult your doctor, pharmacist or other health professional in case of side effects. AVONEX is reimbursed for those patients who meet the special authority criteria in the Pharmaceutical Schedule. Normal Doctors' fees and pharmacy charges apply. AVONEX (interferon beta-1a) is indicated for the treatment of relapsing forms of multiple sclerosis (MS) to slow the progression of physical disability and decrease relapse rates. Before starting AVONEX, please tell your doctor if you have ever experienced, or are currently experiencing, depression or other mood disorders, seizures, blood or heart problems, liver disease or kidney problems. AVONEX is NOT recommended for pregnant women or those who are planning to become pregnant. People who have had an allergic reaction to interferon products or to any other ingredient in the medicine should NOT use AVONEX. AVONEX must not be used by someone who is severely depressed or having suicidal thoughts. Many people who take AVONEX will experience flu-like symptoms (e.g. fever, chills, sweating, muscle ache and fatigue) early on in their therapy. These effects are usually manageable and often diminish with continued treatment. For more information, please refer to the Consumer Medicine Information booklet or call the AVONEX Helpline on 0800 286 639 (0800 AVONEX). This number is for enquiries concerning AVONEX therapy from patients already prescribed AVONEX. For further information see the Consumer Medicine Information for AVONEX at www.medsafe.govt.nz. Medicines have benefits and some may have risks. Always read the label and use strictly as directed. If symptoms persist or you have side effects see your doctor or pharmacist. Ask your doctor if AVONEX is right for you.

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biogen idec[®]

MS Auckland AGM

We held our AGM/Research Day early May and over 80 people attended, including Members, Committee Members and Carers. The feedback we received from this day was extremely positive and many of those that attended would like two Research Days a year. Sadly we don't have the funding for this, however we always make sure we provide knowledgeable and informative speakers that can update the audience on the latest happening in the world of MS.



One of the most repeated comments from the feedback forms were, the day is too long. It is so hard to fit so much in and keep the presentations short and sweet. Next year we are only going to have three speakers and any time at the end can be used for questions. For those of you who have never attended, I encourage you to make a point of it next year – this Research Day is invaluable.

The treatment of the Multiple Sclerosis Disease – what is currently available and what treatments are under development

An increased understanding of the cause of multiple sclerosis (susceptible genes, environmental triggers followed by immune activation) has resulted in the development novel therapies. The aims of current treatments are to minimise relapses and most importantly impact on the accumulation of disability. In 2014, approved treatments are all for the inflammatory phase of relapsing remitting multiple sclerosis (RRMS). This phase of the disease is characterised by the presence of relapses. The beta-interferons and glatiramer acetate are treatments that are funded in New Zealand for a particular group of patients with relapsing remitting multiple sclerosis. Natalizumab and fingolimod are examples of more effective treatments for RRMS but this greater efficacy comes with potentially serious side effects. Natalizumab works to block white blood cells from accessing the central nervous system. Fingolimod has a similar mechanism of action and prevents white blood cells from exiting lymph nodes, gaining access into the blood and from the blood migrating into the brain and spinal cord. Currently in New Zealand, there is no government funding available to pay for access to these newer therapies.

The neurodegenerative or progressive phase of MS disease is the main focus of MS research. All treatments of this stage of the illness remain experimental. Potential therapies for the progressive phase can be divided into neuroprotective, remyelinating and neurorestorative. Statins are an example of a potential neuroprotective agent. Recently published early trial data indicates these medications may reduce the loss of brain cells. Anti-lingo medications are an experimental treatment that



promote premature oligodendrocytes to remyelinate damaged nerves. Neurorestorative treatments are described as the “holy grail” of MS therapy. These also are therapies still under development and not used by doctors to treat multiple sclerosis at present. This type of treatment aims to promote regrowth of damaged nerves or replacement of lost nerves by new nerve cells. Mesenchymal stem cell research evaluates whether changing the chemical environment in which nerves are trying to regrow after being damaged improves their recovery.

To summarise, we have effective treatments for the inflammatory phase of multiple sclerosis. This phase is identifiable to patients and doctors by the presence of relapses. Unfortunately we have limited availability of the medications due to their high cost and are awaiting funding decisions by government agencies. The progressive form of multiple sclerosis results from reduced function or loss of nerve cells. There are a number of potential targets for treatments of this phase of the disease but these remain experimental.

G Giovannoni

<http://multiple-sclerosis-research.blogspot.co.nz/2013/05/lingo-promising-remyelination-target-in.html>

Altering Monocyte responses during Multiple Sclerosis



Anne Camille La Flamme

Head, Multiple Sclerosis Research Programme, Malaghan Institute of Medical Research. Associate Professor, Victoria University of Wellington

For many years my research has centered around understanding how the macrophage, a type of immune cell, works and what role this cell type plays in Multiple Sclerosis (MS). At this point, you may very well ask, "What are macrophages and why are you interested in them?" Both good questions. Macrophages are a type of innate immune cell; that is, they comprise your first line of defence against infections. The term "macrophage" means "big eater" because they are very good at eating and ingesting bacteria or dead cells. They are ubiquitous and found throughout the body. Circulating in the blood, they are called "monocytes" while they are called "macrophages" if they reside in the tissues. Sometimes these tissue-resident macrophages are given special names such as microglia, which are macrophages that reside in the brain and spinal cord. In general, a macrophage is a jack-of-all-trades; these cells can do many different things although they are not particularly good at any one of them. Together these features (big eater, ubiquitous, and jack-of-all-trade) make these cells both sensitive to the immune environment but also able to change the immune environment, and are the primary reasons why I have been so fascinated with them for years.

Altering Monocyte Responses

A recently completed project in my laboratory investigated how monocytes were altered during MS and how the MS treatment, glatiramer acetate (GA; Copaxone) affected monocytes. We found that compared to monocytes from healthy subjects, monocytes from MS patients, who were not receiving any disease modifying therapies like GA, had a more inflammatory profile and when activated could more effectively drive inflammation. Importantly when we compared the profile of monocytes from MS patients treated with GA, they resembled those from healthy patients. Together this work suggests that GA treatment, which had previously been thought to target another immune cell type (T cells), also modifies monocytes by making them less inflammatory.

The first part of this study has been published in *Immunology and Cell Biology* (Chuluundorj et al. 2014. Expansion and preferential activation of the CD14+CD16+ monocyte subset during multiple sclerosis. *Immunol. Cell Biol.* In press. ePub Mar 18). The second part of the study is being prepared for publication. We would like to thank all of the volunteers, who so generously donated their time and blood for this research, and the organizations who funded the work – the Wellington Medical Research Foundation and the Great New Zealand Trek Charitable Trust.

Clozapine treatment for MS

Within the last few years, we discovered that the atypical antipsychotic agent, clozapine, reduces disease severity and duration in our experimental models of MS. Clozapine has been used for decades to treat mental health disorders such as schizophrenia, so it is a well known drug that has been administered to a large number of people. Interestingly, we discovered that the way in which it reduces disease in MS is distinct from how it works in psychiatric disorders. In particular, we find that clozapine is very effective at making the microglia (the resident macrophage population) in the brain less pro-inflammatory. Our principal goal now is to design and run a small clinical trial to begin to assess its acceptability and effectiveness in MS patients. Hopefully we will soon secure funding for this trial so that we can quickly translate our findings into a new therapeutic option for MS sufferers. We would like to thank the Neurological Foundation of New Zealand, who have generously supported this exciting project so far.

For further information, please speak to your Field Worker first.

Reducing stress in a Life with MS

For many decades, people with MS have been telling their GPs, Neurologists, family and friends, that stress makes their MS worse. Research literature is now slowly catching up to the anecdotal evidence provided by PwMS, fuelling our need to take stress management in MS seriously.



Dr Sally Shaw
BSc., Grad Dip Psych.,
DPsych (Health)

What can lower stress levels in MS?

The first place to start is to take a realistic and objective look at what is going well in your life, and what may need some more attention. When looking specifically at living with MS, people should try to be objective, educated, and aim to live within a Health and Wellness Framework. Things to consider include:

Health & Research

Education - Do you have the level of knowledge that you need, to make appropriate decisions regarding your health?

Exercise and Nutrition - Do you act in accordance with your beliefs; based on the knowledge you have about what is healthy for you?

Medication and Symptom Management - Are you communicating effectively with your health professionals and accessing robust advice to manage your disease and symptoms in the best possible way?

Employment and Practical Strategies - Do you know who to speak to if you need help/advice?

Stress Management - Can you identify your daily hassles and chronic stressors (naming them is the first step in stress management). Can you prioritise effective management of your stress?

Psychological/Emotional/Social Support - How do you communicate with you family/friends about your health? Is it effective?

Spirituality and Finding Meaning - Life is short. Taking time to examine what you want to get out of it is strategic, and the only way to stay on track.

Once you have explored these questions, get involved in some daily stress management techniques. These include establishing routines like exercise, meal times, relaxation periods and bed time. Spending time with people who care about you, and talk to them about everything (including areas of difficulty in your life). Stop counting your 'screen time' as relaxation and call it what it is - escapism. Escapism is fine... But make sure you try to incorporate active relaxation into your routine also. Try the Smiling Mind app - it's a good place to start! And lastly, notice your self talk, and try to be kind to yourself, prioritise things that are truly important to you, and recognise joy and laughter in your life.

An easy activity that could prove enormously beneficial both in reducing stress and increasing positivity in your life, is keeping a Gratitude Journal.

Dietary considerations in MS

There is a lot of interest in dietary modification among people with MS. In a study from Germany, just under half of people with MS had tried dietary intervention of some kind. Lipids form the main component of the myelin sheath that surrounds nerve cells. They also form the basic building blocks of the immune



Emily Hadgkiss

system chemicals and play an important role in inflammatory processes.

The interest in diet and MS first came about following the publication of some early population studies that found associations between dietary intake and MS risk. For example, a study from Norway found that people living in the inland areas where livestock and dairy farming were more common, had around a 4 fold higher incidence of MS than those living in coastal regions where fish consumption was higher and the consumption of animal fat, lower. Beginning in 1949, neurologist Roy Swank enrolled 150 MS patients in a study and commenced them on a very low saturated fat diet, supplemented with cod liver and vegetable oils. The findings after 34 years showed that regardless of level of disability at entry to the trial, those adhering strictly to the diet did not deteriorate significantly. This prompted more interest in the role that nutrition might play in slowing disease progression, and many observational and clinical studies have since demonstrated compelling results.

The growing evidence and demand for more information about dietary modification and other lifestyle factors in MS, led Prof George Jelinek and a team of researchers at St Vincent's in Melbourne to commence the Health Outcomes and Lifestyle Intervention in Sample of people with Multiple Sclerosis (HOLISM) study. The study enrolled around 2,500 people with MS from 57 countries who contributed comprehensive data about their diet and lifestyle behaviours and a range of self-reported MS health outcomes. Recently, they published results on dietary intake among people with MS in the journal Nutritional Neuroscience. The study found that people consuming a more healthy diet reported significantly better quality of life and less disability. Most notable were the findings for those with the healthiest intake of dietary fat: compared to the poor fat subgroup, the healthy fat group predicted a 12 point increase in physical health-related quality of life and an 8 point increase in mental health-related quality of life (on a scale from 0-100). They also had a 42% reduced odds of greater disability. Those consuming a higher intake of fruit and vegetables were also more likely to report better physical and mental health-related quality of life and less disability. The data also showed trends towards fewer relapses over a 12 month period for participants with relapsing-remitting MS who consumed a more healthy diet.

The study currently represents data as a snapshot in time; a follow up of all participants is planned to commence in November this year and the research team encourage everyone with MS to get involved. The findings are supported by a recent study from the Tasmanian MS Longitudinal Study that found associations between the blood lipid profile of people with MS and their baseline level of disability and disability progression over 2.5 years.

For more information about the HOLISM study findings or dietary modification in MS, visit www.overcomingmultiplesclerosis.org

Tackling progressive MS

A new 2014 MS Research Australia project grant holds particular promise for tackling the progressive forms of MS. This is an important area of research, since there are currently no treatment options for these forms of the disease.

Associate Professor David Brown at the University of NSW has been awarded \$250,000 over three years to investigate a molecule known as MIC-1/GDF15 that appears to play a key role in regulating cells of the innate immune system.

The innate immune system is generally the 'first line' of defence against perceived threats to the body. It is also involved in longer term clean-up and repair responses to damage. The attention of many researchers has increasingly been turning to the role of the innate immune system in MS as it appears to play a significant role in the 'slow-burning' accumulation of myelin and nerve damage that occurs in progressive forms of MS.

The research program discovered the MIC-1/GDF15 molecule, and as a result of this research, the molecule is now being developed internationally as a new therapy for a number of diseases including obesity and inflammation. Preliminary evidence from his laboratory suggests that MIC-1/GDF15 also modulates the innate immune system and that it may be an effective treatment for progressive MS.

The focus of this project will be the mechanisms by which MIC-1/GDF15 regulates the cells of the innate immune system, such as dendritic cells and the microglial cells of the brain. He also aims to use laboratory models of MS to obtain evidence that MIC-1/GDF 15 could be used as a therapeutic agent in autoimmune disease.

Since MIC-1/GDF 15 is about to enter Phase I clinical trials for appetite suppression, much of the safety work in humans is underway. This means that if Associate Professor Brown can confirm a role for MIC-1/GDF 15 in MS there will be an exciting opportunity to rapidly progress his experimental results into direct benefits for people with progressive forms of MS.

With his considerable experience with this molecule and the tools and methods already developed at the University of NSW, Associate Professor Brown is well positioned to make rapid progress on this exciting project.

Ref: MS Research Australia – Next Issue 34 March 2014



Professor David Brown

Breaking News from Biogen in May

ANTI-LINGO-1 FACT SHEET

OVERVIEW

Anti-LINGO-1 is Biogen Idec's investigational monoclonal antibody currently in Phase 2 clinical development for the treatment of Multiple Sclerosis (MS).

PROPOSED MECHANISM OF ACTION

Anti-LINGO-1 is a fully human monoclonal antibody that targets LINGO-1, a protein expressed selectively in the central nervous system (CNS) that is known to negatively regulate axonal myelination and axonal regeneration.¹

- Myelin is a fatty substance that surrounds and protects nerve fibers in the central and periphery nervous system, promoting effective transmission of nerve impulses.

- In certain diseases like MS, the immune system attacks the myelin in the CNS – causing damage or destruction. This process is called "demyelination." As the damage progresses, nerve cells and axons may eventually die, contributing to sustained physical and cognitive disability.²

- The role of LINGO-1 as a negative regulator of myelination in the CNS was discovered at Biogen Idec. In multiple animal models of demyelination, a relationship between the blocking of LINGO-1 and the promotion of myelin repair and improved functional recovery has been demonstrated.³

CLINICAL STUDIES

Biogen Idec has completed two placebo-controlled Phase 1 studies with anti-LINGO-1. These studies included both healthy volunteers and subjects with MS.

Key findings from the Phase I studies:⁴

- Following a single IV dose in healthy volunteers and two repeated IV doses in MS subjects, anti-LINGO-1 appeared to be safe and well tolerated.

- Anti-LINGO-1 pharmacokinetics in serum and CSF appeared to be similar between healthy subjects and MS subjects.

These findings supported advancing anti-LINGO-1 monoclonal antibody into the Phase 2 clinical study that is underway.

Below is a link to view and we have attached the fact sheet for you.

<http://video.cnbc.com/gallery/?video=3000268932&play=1>

1. Mi S, et al. Nat Neurosci. 2004;7:221-8. Mi S, et al. Nat Neurosci. 2005;8:745-51.

2. Chari DM. Remyelination in multiple sclerosis. Int Rev Neurobiol. 2007;79:589-620.

Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17531860>. Accessed February 25, 2013.

3. S Mi, et al. The International Journal of Biochemistry & Cell Biology. 2008;40:1971-78.

4. Tran J, et al. Neural repair/rehabilitation. Safety, Tolerability and Pharmacokinetics of the Anti-LINGO-1 monoclonal antibody BLIB033 in healthy volunteers and subjects with multiple sclerosis. Neurology. 2012; 78 (meeting abstracts):2-21.

Health & Research

Interesting Links

An Australian study (January 2014) reported in the Journal of the International Society of Behavioural Medicine, concluded that Hope is a potent protective resource for pwMS. Importantly, in terms of clinical practice the authors suggest that there are benefits in promoting Hope in pwMS.

Details are at <http://www.msnetwork.org/ccsviqol.htm#hope>

Peter Sullivan. On behalf of Multiple Sclerosis Network of Care, Australia. <http://www.msnetwork.org>

Hi Folks,

World MS Day – Looking Backwards to the Future - Acknowledging the Australian CCSVI Early Adopters

In May 2011, as an adjunct to World MS Day, the issue of CCSVI and Multiple Sclerosis was first raised in the Australian Parliament. Subsequently all 225 parliamentary representatives were lobbied to put in place "Policies and programs to support the advancement of CCSVI medical knowledge while, at the same time, addressing the ongoing CCSVI needs of Australians living with MS".

Find out what has since transpired.

Details are at <http://www.msnetwork.org/ccsviqol.htm#hope>

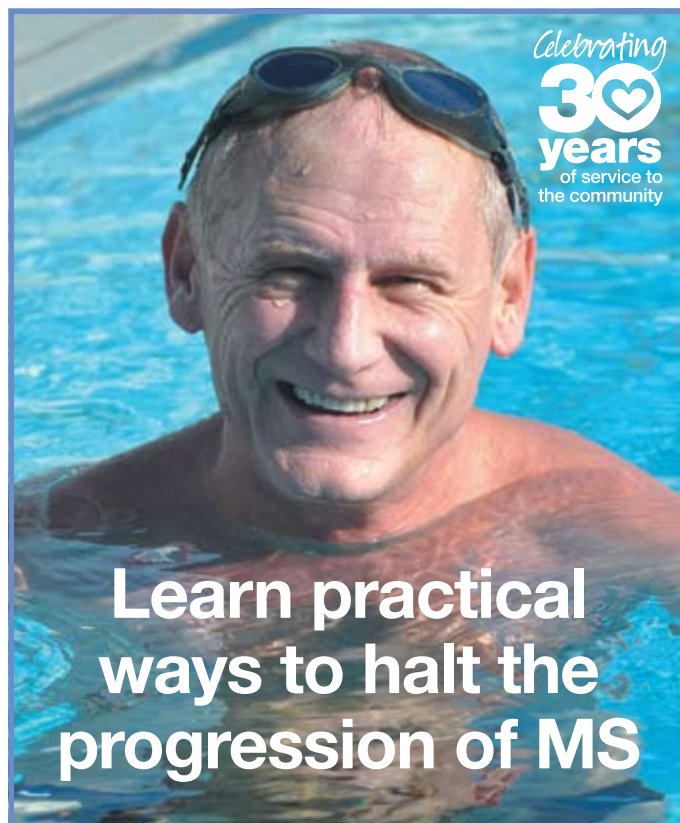
Peter Sullivan. On behalf of Multiple Sclerosis Network of Care, Australia. <http://www.msnetwork.org>

<http://www.dailymail.co.uk/health/article-2576316/Good-lord-Im-beating-MS-How-Earl-Durham-fighting-illness-veggie-diet-meditation-doses-sunshine-vitamin.html>

Library

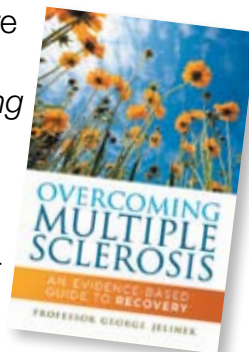
"Whatever the mind of a man can conceive and believe, it can achieve." - Napoleon Hill.

THINK AND GROW RICH TODAY combines Napoleon Hill's original text with insight from Catherine Newton and a panel of other experts about how they used his timeless principles to achieve success they'd only dreamed of.



Overcoming Multiple Sclerosis Retreats The Gawler Foundation, Australia

Teachings at the retreat are based upon Prof George Jelinek's book 'Overcoming Multiple Sclerosis' and The Gawler Foundation's 30 years of experience in lifestyle medicine and self-help healing programs.



"I went to the Overcoming Multiple Sclerosis retreat feeling broken and was given the tools to put myself back together"

Karen (QLD)

The Overcoming Multiple Sclerosis Retreat complements prescribed medical treatments.

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