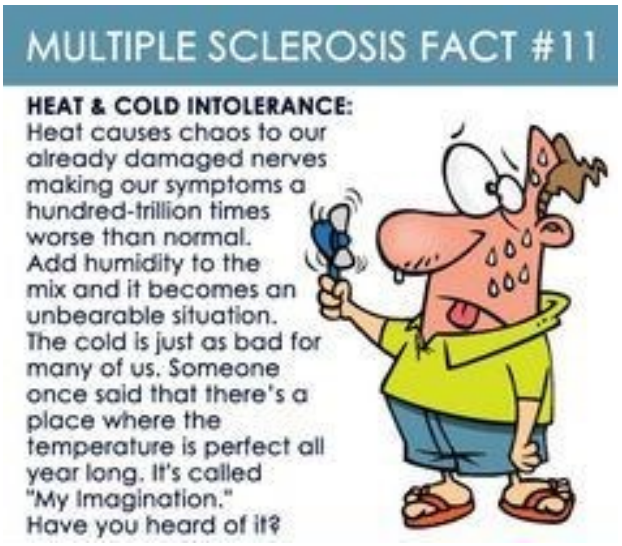
April Newsletter

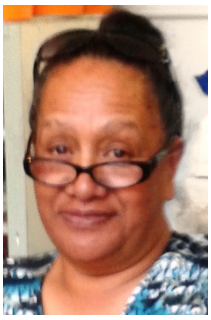
Edition 2, 2016

ms. Wanganui

Inside:



President's Message



Kia Ora Koutou, (hi everyone) Gosh I don't know where the time has gone, it's now April, another two months and half the year will have passed us by.

It is a pleasure to welcome Jody Tapa to MS Wanganui, our new Field Worker, we are excited to have you join our staff and we hope you will enjoy working with our organisation.

The MSNZ Draft Strategic Plan 2015 to 2020 is now finalised, if you would like a copy please ring Gary on 345 2336 or 022 659 4331

Kiss Goodbye to MS, is an international organisation which will have a collection on 29 May 2016. This is a first in New Zealand. The organisation works to fund cures and research into MS. If MS Wanganui supports the work they do, then 10 per cent of our fundraiser will go to the organisation.

I would like to acknowledge and thank those raffle sellers that have helped with the selling of the tickets in our Autumn raffle. You are very much appreciated. Thank You.

The board is due to begin its Strategic Plan Process, so we will be looking to have a consultation process with our membership and those that may be interested.

Events coming up:

World MS Day 25th May 2016

Charity Auction – Date yet to be confirmed

Kiss Goodbye to MS – 29 May 2016

Well that's all for this month, I leave you with a motivational quote:

"Life is 10% what happens to you and 90% how you react to it".

By Charles R. Swindoll

Veronica Kapaiwai

President

Field Worker's Report

Hi. My name is Jody Tapa and I am the new Multiple Sclerosis Field Worker for the Wanganui Region. I have taken over Carol Hammond's position (I understand that I have big shoes to fill…).

I originally come from the Wanganui River, however I have only recently moved home after spending 20 years in Auckland and 5 years in Raetihi.

I come from a Social Services, and Counselling (Alcohol and Drug specific) background. I have worked in Social Services and Counselling Services for the past 15 years and found it very rewarding. I also have been around people with disabilities for most of my life as my step father is a tetraplegic and very active in the disabled community.

I previously managed an organisation for 4 years called "Parafed Auckland" which provides sporting opportunities for people with physical disabilities this too is a NGO based at the Otara Spinal Unit.

I recently had the privilege to attend the Multiple Sclerosis Field Workers Regional meeting. I found this very informative and it was a pleasure to meet with other MS Field Workers. We discussed the different activities that were getting implemented in other areas. I thought I would take this opportunity to share them with you all to see if any of our MS Members would be interested in starting similar programmes up here. Here are some of the activities:-

- Wellness Groups – Client driven support and information sharing group
- Yoga groups
- Pilates Groups – funded by Southern Trust
- Swimming groups – Aqua exercise contracts that local MS societies have with their local swimming pools
- Art classes
- Nutrition training and how it can minimise symptoms
- Brain Gym - this is a support group for MS clients that challenges them to use the brain through Bingo Board games, guest speakers etc
- Fatigue Courses and how to minimise fatigue

If anyone is interested in participating in any of these groups then we can definitely look at starting some of these up providing there are the numbers to attend. Also if anyone has any other ideas then please feel free to call me and have a chat about it.

A reminder too we have a support lunch every third Thursday of the month all are welcome, for any details please contact the MS Wanganui Office.

I look forward to spending time with you all in the future.

Jody Tapa

Field Worker

ms. Wanganui

Jody Tapa
Field Worker

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Italian Tofu Meatballs

Ingredients

300g tofu mashed
1 onion very finely chopped
1 clove garlic
¼ cup ground almonds
2 slices bread crumbled
2 tablespoons flour
2 tablespoons finely chopped parsley
2 tablespoons soy sauce
1 teaspoon dried basil or handful fresh basil, plus extra to garnish
Oil spray to grease

Preparation

Preheat oven to 200₀C. Combine all ingredients, except oil in a bowl (I put all ingredients into a food processor to be chopped & combined). Mix well.

Shape into 16 – 20 balls (depending on the size) Spray a non-stick baking dish (baking tray) with oil (or line with baking paper). Place tofu balls on prepared dish and bake in oven for 15 minutes. Turn tofu balls over and bake for 15 more minutes.

Toss tofu balls with rice or pasta and your favourite tomato sauce. Serve sprinkled with fresh

MULTIPLE SCLEROSIS FACT #12

SPEECH PROBLEMS:
Aside from the long pauses we take as we search to remember words, our voice can sound weak, winded, choppy and soft. Many times people will ask us to speak up, and although we would like to and even try, we can't seem to get the words out any louder. Drive-thru ordering can be comical. "So, you want lettuce and popcorn on your hamburger? Really?" Regardless, we have a lot of wisdom, so pause and take the time to hear it.

MULTIPLE SCLEROSIS FACT #13

EMOTIONAL CHANGES:
Mood swings are real and we have them more than we like to admit. We have been known to burst out laughing at the most inappropriate times, like when someone is sharing a sad story about how their pet fish died. We also cry for no reason, get angry faster than normal and become extremely frustrated at things that never frustrated us before. After all, our life has flipped upside down and we are living in a world we don't understand anymore.

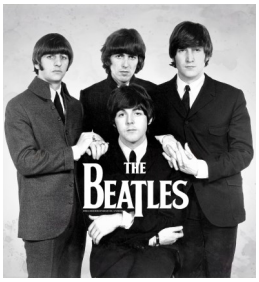
NEW DRUG OZANIMOD COULD BE AN EFFECTIVE ALTERNATIVE TO FINGOLIMOD

An international study looks at the safety and efficacy of a drug similar to fingolimod

For the past few years, neurologists have been successfully using fingolimod (an oral tablet) for people with relapsing-remitting MS. However, because of the adverse effects it can have, such as changes in heart rhythm or eye problems, researchers are looking to find a similar drug that maintains the desired effects but causes less adverse events.

Ozanimod could be the solution to this problem. As the first step toward approving the drug, this international study carried out in fifty five MS centres across Europe and the USA, looked at potential unwanted effects of ozanimod. It also assessed whether ozanimod was safe to be taken by people with relapsing-remitting MS.

The final results were positive, showing improvements in MRI of people with relapsing-remitting MS. The next is to confirm efficacy in a larger phase III trial, which is ongoing.



BEATLES SONGS WORD SEARCH

Find and circle all of the songs by The Beatles that are hidden in the grid.
The remaining letters spell the name of an additional Beatles song.

W D H E Y B U L L D O G E T B A C K A
A R E T T E B G N I T T E G S H E P S
I E Y A D H T R I B B N O R E P L Y K
T C D A R W O P O L Y T H E N E P A M
S A M I O P D H A S Y N O P A G I D E
E E T O R N R C D R U L I S N F T H W
X G F I E O K U C A A N E R E I O U H
Y U N E R B T Y D D R P K Y G X Y R Y
S E H I I Y B T Y E L L B I S I B E Y
A T F R H A L M E E N D I E N N G P H
D H D I B T A E A K O C U N L G I P W
I H E Y L D E S V O C L E L G A R I E
E T R Y O Y E M G O B I E H E H R R M
T C B N J M M O O R L F T A T O O T L
A H N U E U L N E S I I W I L L N Y L
X A L R O L D Y I F L Y I N G E A A E
M I C H E L L E I P Y E N O H O E D T
A M W H I N Y A D R E T S E Y D L O W
N L R I G R E H T O N A E N I M E M I

ANOTHER GIRL
ASK ME WHY
BIRTHDAY
BLACKBIRD
CRY BABY CRY
DAY TRIPPER
DEAR PRUDENCE
DIG A PONY
ELEANOR RIGBY
FIXING A HOLE
FLYING
GET BACK
GETTING BETTER
HELLO GOODBYE
HEY BULLDOG
HEY JUDE
HONEY PIE
I ME MINE
I WILL
IF I FELL
IN MY LIFE
JULIA
LADY MADONNA
LOVELY RITA
MICHELLE
NO REPLY
OH DARLING
PLEASE PLEASE ME
POLYTHENE PAM
SEXY SADIE
SOMETHING
SUN KING
TAXMAN
TELL ME WHY
THE END
TICKET TO RIDE
TWO OF US
WAIT
YER BLUES
YESTERDAY

Coffee Consumption and Risk of Multiple Sclerosis

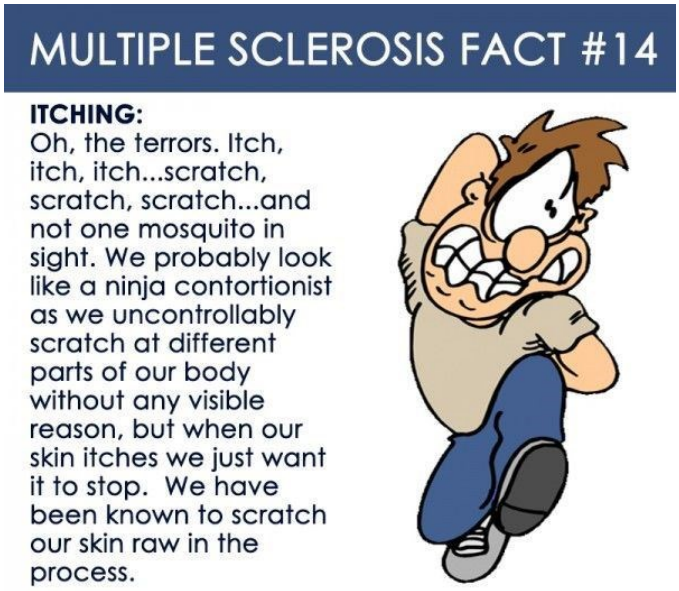
Research suggests that high consumption of coffee may protect brain cells from damage

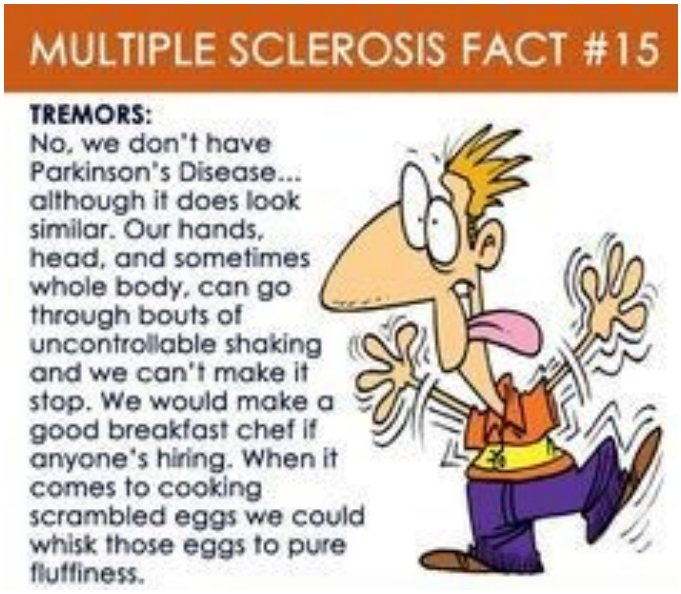
Caffeine is one of the main components in coffee, and researchers working on animals have shown that it might protect brain cells from damage. Loss of brain or spinal cord cells contributes to disability in MS.

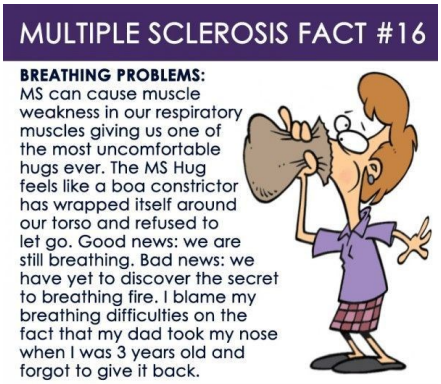
Swedish researchers have looked at questionnaires from thousands of people with MS, as well as those from healthy volunteers, where participants reported their coffee consumption habits. The researchers found that people who consumed more coffee per day (900 ml or approximately 6 cups) were less likely to have MS.

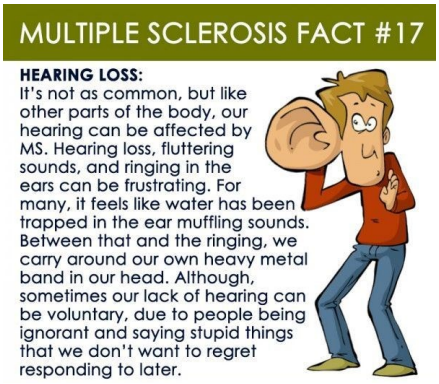
The effects of coffee were independent of whether subjects had been drinking coffee at the start of the disease, or 5 or 10 years before the start of the disease. Similar effects have been observed in other brain diseases, such as Parkinson's disease.

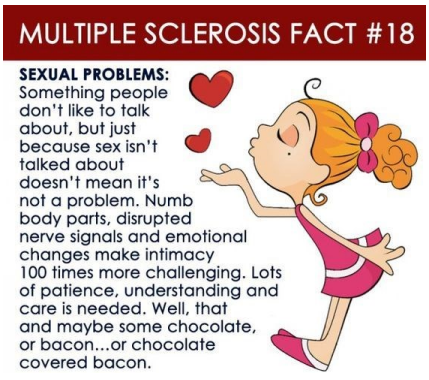
This study, however, does not provide any evidence of a causal relationship between drinking coffee and MS, and further studies are needed to establish such a link and to understand how coffee might be reducing MS risk.











Epilepsy Drug Could Protect Nerves From Damage in MS

A drug currently used to treat epilepsy could be used to protect cells in the optic nerve for people with all types of MS

An epilepsy pill called Phenytoin might be effective in protecting nerve cells in the brain against disease processes during MS. Blurred vision is a common problem for people with MS, which usually is the result of inflammation of brain visual wirings (optic nerve). The inflammation can gradually cause death of visual cells which contributes to long-standing visual problems. Researchers have shown that Phenytoin, which they administered in parallel to approved medications for MS, can protect brain visual pathways from death (neurodegeneration).

This study was a phase-2 trial with only a short follow-up, which means the next stage of research will be to prove the effectiveness of this proposed drug in a larger number of people. However, the results are promising to introduce new therapies that can keep brain cells healthy. Furthermore, developing a drug from scratch is a painstaking process that can take decades to get from laboratories to trials. Here, researchers used a drug already available in the market, which shortens this time dramatically.

This study was funded by two members of the Progressive MS Alliance and was led by a member of its Scientific Steering Committee, Raj Kapoor (from the UCL Institute of Neurology).

Obesity and MS

How common is obesity in people with MS and is it related to disability?

While several studies have shown that many people with MS are overweight, the impacts on the disease of having a high body mass index are not well studied in MS.

Australian researchers have looked at a large number of questionnaires from people with MS, where they found obesity was related to lower quality of life and higher disability.

Obese people with MS or those who were smokers had a higher chance of having other diseases, such as diabetes or high blood pressure. While these findings do not show any cause or effect relations with MS, a healthier life style that can keep your weight stable, will have beneficial effects and may slow the progression of disability

Natalizumab is More Effective Than Fingolimod in Reducing Relapses

French researchers compare oral and injectable drugs for relapsing-remitting MS

The emergence of new disease modifying treatments in tablet form in comparison with the injectable drugs is a triumph for the MS field. With new options for treatment, however, choosing the best drug at a specific point during MS course is more difficult than before for both people with MS and neurologists.

In this study French researchers asked whether an oral therapy (fingolimod) is better than a potent injectable drug (natalizumab) for preventing new attacks or the appearance of new lesions on MRI.

The results show that natalizumab is more effective. The usage of natalizumab, however, should be balanced against rare, but serious adverse events (such as Progressive multifocal leukoencephalopathy (PML), brain inflammation resulting from the JC virus) that are not seen as frequently in fingolimod.

Brain Fog Explained

Cognitive issues, colloquially known as 'Brain Fog', are a common complaint of people with MS, with an estimated 70% of people progressing to report problems with thinking, concentration or memory.

A recent study published in the Journal of Neuroscience sheds new light on damage caused by MS, specifically in the brain, which may help to explain this cognitive decline and consequently help researchers to target effective treatments.

Lead author of the study, neurologist Matthew Bellizzi, notes that the research identifies a new disease mechanism in MS which causes damage to neurons independent of the demyelination which normally characterises the disease. This, he explains, represents a further component of the disease and importantly, is one that is not prevented or controlled by the current range of disease-modifying immunosuppressive drugs used to treat MS.

The drugs which are currently at the disposal of physicians are effective in suppressing the attacks which lead to myelin damage, however they are ineffective in the prevention of cognitive issues. Hence, researchers speculate that there may be additional, as yet not fully understood, damage occurring in the central nervous system.

Senior author of the study, Harris Gelbard, feels that for too long MS has largely been discussed as a disease which affects sensory or motor functions, yet for many patients it is the loss of cognitive ability which has the greatest impact on their quality of life.

The research team carried out experiments in mouse models of MS, and showed that neurons in the hippocampus (an area of the brain not associated with motor control) were being damaged at the synapse, which is the point where cells communicate with each other via the transmission of chemical signals. And, responsible for this damage they report, appears to be the microglia – a cell in the central nervous system's defences.

The primary role of the microglia is to fight infection or other attacks on the nervous system, and to clean up the damaged cells, but it also serves to preserve the health of the synapse so that it functions normally and aids the hippocampus with cognitive abilities such as learning and memory.

The problems therefore occur when the immune system is over-stimulated during MS, and the microglia receive distress signals which prompt them to switch from their protective, nurturing role to an aggressive, pro-inflammatory response.

During this reaction, they release the molecule PAF (platelet-activating factor), which affects the signalling that neurons use to activate one another. High levels of PAF cause over-activation of these signals and actually serve to destroy the receiving end of the synapse. Consequently, more microglia and other immune cells rush to the site, which triggers a cycle of destruction. The researchers felt that the cumulative effect was like trying to put out a fire with gasoline.

It is this phenomenon which the researchers believe is largely responsible for the greater part of the cognitive damage and over-time decline that people with MS experience. Due to the activation of microglia being unaffected by current MS drugs, research is now focussing on potential therapies which could suppress the signalling pathways which result in nerve cells and microglia becoming overactive.

Amongst the potential candidates is a drug which is being investigated in the treatment of HIV-associated neurological disorders. It is interesting to note of course that the OMS Recovery Program works precisely through this mechanism of switching the immune system from an over-stimulated mode (Th1 response) to a more quiescent mode (Th2 response); there is every likelihood that this helps to put out the fire around the synapses in the central nervous system.

MULTIPLE SCLEROSIS FACT #19

HEADACHES:
Our headaches can be caused by many things: medications, lack of sleep, damaged nerve receptors, depression, a bladder infection, steroids, stress, and of all things... annoying questions. "Have you taken an aspirin?" is not an appropriate question to ask us about our pain. Neither is a response telling us it's all just in our head. Really? MS...in our head? Who would have thought?

MULTIPLE SCLEROSIS FACT #20

SEIZURES:
Not all seizures are the same. It's possible for us to have the typical kind with uncontrollable jerking movements, but we can also experience lapses of consciousness without any movement at all, experience a "drop attack" where our legs turn to jello causing us to drop to the floor, and have moments when we appear to be wide awake but are completely non-responsive. Those are all considered types of seizures, not new dance moves.

INVESTIGATING COGNITION TO FULLY ASSESS MS PROGRESSION

Study recommends including cognitive evaluation when measuring NEDA

Many people with MS experience cognitive problems, like memory disturbances or slowing down of information processing speed.

Cognitive functions are harder to measure than clinical disability and MRIs, so they are not routinely evaluated in clinical practice.

The concept of 'no evidence of disease activity' (NEDA) has recently emerged as an important outcome measure for MS in research studies or clinical trials. It means no relapses or disability progression and no new white matter lesions are identified with MRI. However, it is not known if maintaining NEDA has a positive impact on cognition or brain atrophy (shrinkage).

A research team from Italy carried out a study to evaluate the correlation between NEDA status, cognitive functions and brain shrinking.

They followed 42 people with relapsing remitting MS for two years and found that only 30.8% of them achieved NEDA status. About half of those with NEDA status still had deterioration of some cognitive functions.

The recommendation from this study is to include cognitive evaluation in the NEDA measure to comprehensively assess disease progression.

A SPECIAL THANKS TO THE FOLLOWING ORGANISATIONS FOR THEIR CONTINUED SUPPORT!

MINISTRY OF HEALTH
COGS Community Organisation Grants Scheme
Lottery Grants Board LOTTO FUNDS FOR YOUR COMMUNITY
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