

multiple news

Multiple Sclerosis Auckland Magazine

December 2016 | Issue 35

Graeme Sinclair – Embracing life



inside



Graeme Sinclair
reframing diagnosis

keep cool
this summer

food &
recipe

MS pain &
medicinal
cannabis

From all of us at MS Auckland, have a safe and happy holiday season



Shhhh, Aubagio at work

If you're living with relapsing MS, there is a treatment that may suit you.

Aubagio is a well-tolerated treatment that effectively delays disability progression and reduces relapses.

Aubagio, working to help quiet MS quietly.*

A once-daily pill, ask your doctor if Aubagio is right for you.

*Aubagio has demonstrated a significant and consistent reduction in multiple measures of disease activity in relapsing forms of MS, while its most common adverse events included diarrhoea, rashes/itchy skin, which rarely required treatment discontinuation. For full information on side effects, please read the Consumer Medicines Information available at www.medsafe.govt.nz.

Once-daily
AUBAGIO[®]
(teriflunomide) 14 mg tablets

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our people.

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a few words from Ingrid.

Our General Manager

It has been one year now since I joined the Team at MS Auckland. What a great year it's been! There have been so many highlights through the year. I couldn't possibly list them all, but here are just a few.

Meeting many of the MS Auckland family at coffee groups, pool groups, and yoga classes, drinks with the evening social group, visits to care facilities and seeing people in their homes – has been personally very enriching. This past month I met up with 2 very inspirational people in their home, Huhana Hickey and Shirley Buxton. You can read about them in this magazine. I'm sure they will inspire you too.

It's been so rewarding to meet the people who organise fundraising events for us. You are wonderful people. In this issue Hiria Kayes tells us about how she organised her own half marathon event for a group of women and raised over \$2,500!

MS Auckland is blessed with many unseen heroes - people who give their time voluntarily and make everything work smoothly. This magazine will now feature one or two volunteers in each edition. See Judy and Jocelyn's story on page 10.

Research Day was an amazing day! It was great also to connect with Brett at MStranlate, who was one of the keynote speakers. Brett's work is most inspiring. I have continued to work with him through facebook and e-mail communications. A current MStranlate research article features on page 18.

The two main fundraising events we had this year were hard work, but the hard work paid off. Our Life Buoy lunch and charity auction and the Street Appeal were very successful this year – thanks to people like you who support our work. I'm writing this just before our Bike the Bridge event, which is promising to be a lot of fun while also raising awareness and funds for MS Auckland.



Ingrid and Paul Minett collecting for Street Appeal

This year, with Pub Charity funding secured by MSNZ, we contracted Attitude to produce a series of three National MS Awareness Videos. Attitude did a highly professional and excellent job. The two that have been released so far have been widely viewed around the world! Huge thanks to the video stars, Judith, Jonas, Mandy and Julie. You can see the videos on our website www.msakl.org.nz.

Working with the dedicated and hard-working staff and committee at MS Auckland has been a joy. We are now planning and preparing for 2017. Things are always changing with MS, and it is important for us to continue to adapt and ensure that we are always doing the right things for the MS community in the right way. We exist to serve the MS community. And, as Charles Darwin said - *'It is not the strongest of the species that survives, nor the most intelligent that survives. It is the one that is the most adaptable to change.'*

Thank you for a wonderful year. Wishing you and yours a peaceful and fulfilling year ahead.

Ingrid

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events for
your calendar.

December



Christmas Party

Sunday 11th December

1:00 pm

Auckland Commerce Club
27-33 Ohinerau Street, Remuera

Members - \$25 | Non-Members - \$35
Cash Bar

RSVP to events@msakl.org.nz or ph 09 845 5921



ms.
Multiple Sclerosis
AUCKLAND

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from the field.

Keep cool this summer!

It's nearly that time of year again... Summer! If you are someone who is affected badly by heat, you are probably dreading how to survive this upcoming season. In this article, I will review different strategies and aids that could help you to **cool down!**

50-80% of people with MS find that their MS symptoms become exacerbated when they get too hot. Disruptions to autonomic and endocrine functions can also occur. Temporary changes in symptoms associated with heat are referred to as Uhthoff's phenomenon. This happens because increased temperatures can prevent nerve fibres from working effectively.

Additionally, in some people with MS, sweat function is impaired – and sweating is a natural way that bodies work to cool people down.

If you're lucky enough to have air conditioning, maintaining a stable environmental temperature is great to prevent overheating and symptom flares. But what if you don't have air conditioning or you want to leave the house? ... Not to worry! There are some products and strategies that can help you to cool down.

Strategies to try: The most basic (and cheapest!) ways of cooling down are:

- drinking cold/icy liquids
- sucking ice cubes
- taking a cold bath or shower (starting lukewarm, and slowly making it colder)
- sitting by a fan or breezy spot
- precooling (using cooling methods before being exposed to heat stress) can also help

If you're on the go, taking an icy beverage in a thermos, Chilly Bin or Chilly Bag could help you to last the distance. It is important not to put ice directly on the skin for the purpose of cooling.

Lifestyle strategies play a big part too.

Avoiding hot environments – indoors or outdoors, seeking out environments with effective cooling, going out early morning or late evening, wearing lightweight and loose clothing, avoiding dark clothing, being sun smart (keeping covered and staying in the shade), closing curtains/blinds and keeping up fluid intake, can all help in preventing symptoms associated with overheating.



Cooling aids: If you feel like you need to be doing more, an external cooling aid could be of benefit. External cooling devices can be either active or passive. Active cooling devices need a power source and work by circulating cooling liquid throughout a garment. Passive cooling aids, which will be focused on below, use gel, ice or another substance that has a cooling effect.

Passive cooling aids come in different forms such as vests, ties, mats and wraps. Cooling garments have been shown to improve neurological function and reduce fatigue in individuals with MS.

Cooling vests, ties and wraps: Out of these, cooling vests are by far the most effective. One company, that has been selling cooling vests and other cooling aids to people with MS for approximately 10 years, is Arctic Heat, based in Australia (see references for website). Arctic Heat report that all feedback received from individuals with MS has stated a significant improvement in their ability to manage heat.



Arctic Heat's vests (and other products) come in blue or white and are made of specific cooling fabrics. They have special crystals sewn into pockets, which are activated and expand into gel form when soaked in water. Once activated, these vests can be used icy cold, cool, wet, damp or dry, and can be stored in the fridge or freezer. The vests can retain their cool temperature for long periods of time and can be worn under or over clothes. To make them last longer, it's a good idea to keep them in a Chilly Bin or Bag, with ice packs, when on the go. For those with sensitivity to cold, they can even be used hot!

These vests work by dropping skin temperature, stabilising core temperature and improving perceived level of comfort. They are not dangerous and are designed so that they will never drop core temperature below a safe 37.5 degrees Celsius. Their other products, such as cooling ties and wraps, are made of the same materials, and can help somewhat with cooling. They are most effective when used in combination with a cooling vest. Cooling wraps can help when you have specific parts of your body that become overheated.



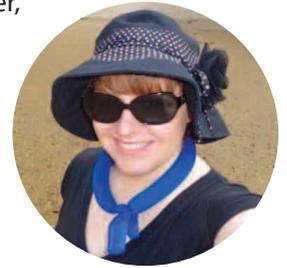
I personally find a cooling tie and a cooling vest to be a great combination, but I keep my cooling ties in the fridge, as they tend to be too cold on my neck if kept in the freezer. I keep my cooling vests in the freezer, and as I wear one, the ice

melts back into gel form, but surprisingly does not make my clothes too damp. Just a tip: If you e-mail Arctic Heat before purchasing a vest, saying you need it for medical reasons, they will give you a discount on the vest.

See references for other places where cooling vests/products can be purchased, but I cannot guarantee their effectiveness.

Other cooling ideas: Do you find yourself waking up too hot in the middle of the night, or heating up the chair/couch that you sit on? In this case, cooling mats and pillows could be of use. These contain naturally cooling grainy or gel substances that have a cooling effect when sitting/lying on them. One website that sells these is Innovations (see references). Gel pet cooling mats are generally cheaper and can work too, although from personal experience, they don't retain their cooling effect for as long as the ones from Innovations. These can be stored in a cool, dark place, such as under the bed and are useful as a short-term cooling option.

What happens if I can't afford any of these products? There are other homemade options that you can try, such as keeping some wheat bags or damp tea towels in the freezer, and putting them on the back of the neck/shoulders when overheating.



Enjoy your summer!

Written by Andrea Kortas,
MS Field Worker

References:

Arctic Heat: <http://www.arcticheat.com.au/>

<http://activemsgers.org/tipstricks/choosingacoolingvest.html>

<http://activemsgers.org/effectsofcoolingonms.html>
Innovations (search 'cooling'):

<http://www.innovations.co.nz/>

Other cooling vests/products:

<http://www.frontmed.co.nz/products/product-details/emergency-care-/cooling-equipment/ferno-cool-vest>

<http://www.daltoninternational.co.nz/Cooling-Apparel---neck-ties--neck-shades--cooling-beanie--cooling-vests>

<http://www.adrienz.co.nz/products.html#coolvest>

<http://www.chilla.co.nz/vest.html>

<http://www.innovations.co.nz/p/home/laundry-cleaning/evpcl-personal-evaporative-cooler>

Our field workers



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Dianne
South
Auckland

Andrea
West
Auckland

Diane
North
Shore

Contact

Carol, Central Auckland – contact 021 959 187

Dianne, South Auckland – contact 021 845 903

Andrea, West Auckland & Rodney – contact 021 959 189

Diane, North Shore – contact 021 859 187

MS sassy – inspirational half marathon event raising funds for MS Auckland.

Motivated by an inspirational friend who herself completed a half marathon whilst suffering the symptoms of MS, we wanted to organise our own event and at the same time raise awareness and funds for MS. Six of us ladies were running each weekend, only about 5 or 6 kms, mainly to catch up for a chat and a bit of exercise together. Contemplating getting this up to 21.1kms was no easy feat for us but what I have learned from all of this is that it is mind over matter! We were all prepared to do some training and have a bit of fun.

The actual event was on Sunday 25th September and the course was along Orewa Beach and then around the Orewa Estuary twice. We each hit up our family, friends, colleagues and neighbours for sponsorship. You could run, walk or bike the course or a combination of all 3. We had amazing support from all our husbands who helped run the day and checked on everyone as they went around the course. We finished off the day with a BBQ and Bubbles!

As the main organiser I was unable to do my run on the 25th of September as I got terribly sick and it has taken me 6 weeks to finally get better and fit again.



Thanks to my Ms Sassy ladies and my supportive husband I was able to run my first half marathon on Saturday 5th November.

For me the best part wasn't about finishing the run but watching our Sassy friend with MS cross the finish line after walking 13.6kms in the rain and wind!

Final totals are not in yet but we are on track to have raised over \$2,500 from this event which we have chosen to donate to MS Auckland.

Hiria Kayes
Ms Sassy Organiser

Gordon and his knitting.

Gordon McGavin has MS. Together with his wife Janice they attend the Manukau Support group meeting at Friendship House on the last Tuesday of the month.

At the August meeting Gordon brought along his knitting to show the group how the loom is used and what type of garments he can make with it.

He also brought along samples of beanies, fingerless gloves, scarves and the beautiful "rainbow" blanket shown in the picture. This blanket is big enough to fit a king single bed and is all done on the loom!

Gordon's hobby has proved to be wonderful therapy for him. Gordon started off with the intent of getting "his fingers to work better" but it has done way more than that. Before commencing the knitting Gordon was having trouble doing up buttons. Now he has no problem doing up small buttons, tying shoe laces and other things that require fine motor skills and that he could not do so well before.



It also keeps his mind active as he works out the patterns on the computer before starting the actual knitting.

Keep it up Gordon as you are an inspiration to us all.

By Dianne Bartlett, Field Worker.

are you a fowl or an owl? Meeting Shirley Buxton, by Ingrid Minett

Shirley celebrated her 90th birthday this year and is our oldest member with MS. I visited her with Diane, her Field Worker, to find out more about this lovely woman.

Shirley has been living with MS for over 60 years now. Her original diagnosis was Peripheral Neuritis. She never felt this to be correct, and it wasn't actually until 1978 that a Neurologist in Melbourne, where she was living at the time, diagnosed her with MS. There is no MS in her family and she had no idea what MS was when she was diagnosed. However she says the diagnosis was a relief. It was good to know that it wasn't all in her head and that all the symptoms she was experiencing were real. Now she had a name for it all.

It is hard to get Shirley to talk much about her MS journey but she does acknowledge that there were bad spells during the 60 years. To look at her now though at 90 years of age, you would never know she has MS. She lives on her own with a daughter not too far away, and a son who helps manage her affairs, just up north. She is expecting her fifth great grandchild very soon. She receives home help for her morning and evening routines. During the day she enjoys reading, receiving visits and phone calls and looking over her beautiful garden. She is as sharp in the mind as I hope to be if I am lucky enough to live to be 90.

Shirley is the last of 7 children. She has lived longer than any of her 6 siblings, as well as her parents. Most of her friends have passed on too, or are living in rest homes.

I asked her what the secret was to her health and longevity. While she claims to have no idea, Diane was quick to announce that she has an incredibly positive attitude on life.



How did she get this attitude? Well "what's the alternative?" she asks, "Just accept things and carry on". Shirley recalls after being diagnosed with MS being taken to an MS ward in a Melbourne hospital. When she saw the people on the ward with the most debilitating of MS symptoms she decided then and there 'this won't be for me'.

She was also a keen swimmer and loves the water. While she has had to give it up now, she would walk down to her local beach each day for years for an early morning swim. "I'm a fowl" she says. I love the early mornings. Then she asks if I'm a fowl or an owl. "I'm a fowl", I say, "but I haven't always been". She tells me, very apologetically that it may be because I'm getting older.

Her goal was to reach 90. Perhaps her positive attitude and regular swimming have helped her in achieving that. Now that she has surpassed that goal, she is happy just living in the moment and taking every day as it comes.

Such an inspirational woman! I'm betting that this lovely fowl will be celebrating a few more birthdays yet!

Taikura Trust and MS Auckland – building stronger relationships.

On the 4th of November MS Auckland and Taikura signed a partnership agreement to have a Taikura Trust member 'hot desk' in our office for one day every 6 weeks. This is part of the Trusts Community Presence programme, aimed at connecting and building stronger relationships and a higher degree of trust and understanding with their key stakeholders in the community.

Taikura Trust (NASC) provides support to disabled people under 65 years and their families and carers across greater Auckland. They work to understand their needs, develop a plan and ensure the best support services are in place to meet their needs.

We enjoyed a morning tea together on the first day, and look forward to working closely with Taikura for the best support possible for people with MS.



profile on volunteers.

MS Auckland relies on volunteers to be able to provide many of our services and programmes. We have so many wonderful volunteers working away quietly for us that we felt it is time to let them shine.

The first 2 volunteers that we would like to shine the spotlight on are Judy and Jocelyn - two amazing ladies who turn up, without fail, every Thursday morning to help out at our Epsom Pool Hydrotherapy Class.

Judy started volunteering at the pool, four years ago, after her daughter (Janine), a swimming coach at the school, over heard the only volunteer at that time, saying how difficult it was with only one person helping out. Janine went home and told her mother. As a result, Judy, a keen swimmer who has swum all her life, turned up at the pool the following week and has been there ever since.

Jocelyn was accompanying her husband, who participates in the group, to the pool each week. After a few weeks of sitting on the side observing, she asked if she could help out. This request that was very willingly taken up! That was almost three years ago and like Judy, Jocelyn has helped out every week since.

These lovely ladies, arrive before the participants to ensure the kitchen and seating area is set up for the morning tea at the end of the session and the swim belts are sorted and ready beside the pool. They then greet all the participants as they arrive and make new people feel welcome.

They ensure all participants are wearing a belt, making sure they are fitted correctly before entering the water. Under the supervision of the physiotherapist taking the class, they assist people into the pool, via the steps or hoist. As the "water baby" Judy is the in pool helper, with Jocelyn on the side-line, signing off the attendance sheet and keeping a general eye on the group. As with all our pool groups, it is important to have one volunteer in the water and one poolside at all times.

At the end of the session, once everyone is out of the water, Judy and Jocelyn race off to the kitchen to make sure a hot drink and cookies are ready and waiting when everyone is dressed. Once the group disperses, after a half hour social catch up, Jocelyn and Judy, clean up the kitchen stack up the chairs and table with the willing help of Jocelyn's husband, Noel.

Jocelyn takes charge of the Koha collected each week and replenishes tea coffee cookie supplies as needed. Judy and Jocelyn help to make the Epsom pool group the smooth running, safe and fun group that it is today.

Thank you, ladies – you are wonderful!



Jocelyn and Judy at Epsom Pool

If you would like to find out more about volunteering for MS Auckland please contact our Volunteer Coordinator, Becky at Becky@msakl.org.nz or phone her on 09 845 5921.

hydrotherapy.

Hydrotherapy continues to be enjoyed by a good number of people although we are always trying to encourage more people to give it a go. The first 2 classes are free, so there is nothing to lose and everything to gain from giving it a go.

Suzie recently joined the Saturday group and writes:
"I really look forward to the hydrotherapy group on a Saturday. It's really good exercise and also a great social time. I couldn't believe it on my first time, when every single person came up to me and introduced themselves - they're such a friendly bunch and they make it fun. I often find I have a lot more energy on a Saturday afternoon now."



Cost

MS Auckland members – first 2 classes free - then \$50 for a book of 10. People with other Neurological Conditions – first 2 classes \$14 - then \$70 for a book of 10

For more information on the sessions, contact Rope Neuro Rehabilitation on 623 8433.

Christmas Closure and New Year Opening

We are winding down for the Christmas holidays. Please note the last day and reopening dates for the pools below:

Pool

Lloyd Elsmore
Millennium
Manurewa
Epsom
Westwave
Dio – (At Mount Albert*)

Final 2016 Classes

Tuesday 13th December
Wednesday 7th December
Wednesday 30th November
Thursday 22nd December
Friday 16th December
Saturday 17th December

Opening 2017 Classes

Tuesday 7th February
Wednesday 8th February
Wednesday 8th February
Thursday 19th January
Friday 10th February
Saturday 21st January

** From the 26th of November until next year the Saturday sessions usually at Diocesan Girls Grammar School will be held at Mt Albert pool - 38 Alberton Ave, Mt Albert*

2016 Weekly Sessions

Tuesday

Lloyd Elsmore Pool

Sir Lloyd Drive
Pakuranga

11.00am - 12.00 noon

Contact:

Dianne Bartlett
09 845 5921 Ext 220
dianne@msakl.org.nz

Wednesday

Millennium Pool

17 Antares Place
Rosedale

10.30am - 11.30am

Contact:

Diane Hampton
09 845 5921 Ext 219
diane@msakl.org.nz

Wednesday

Manurewa Leisure

Sykes Road
Manurewa

11.00am - 12.00 noon

Contact:

Dianne Bartlett
09 845 5921 Ext 220
dianne@msakl.org.nz

Thursday

Epsom Girls

Silver Road
Epsom

10.30am - 11.30am

Contact:

Carol Andrews
09 845 5921 Ext 222
carol@msakl.org.nz

Friday

Westwave Aquatics

20 Alderman Drive
Henderson

11.00am - 12.00 noon

Contact:

Andrea Kortas
09 845 5921 Ext 221
andrea@msakl.org.nz

Saturday

Diocesan Girls

Clyde Street
Epsom

10.00am - 11.00am

Contact:

Carol Andrews
09 845 5921 Ext 222
carol@msakl.org.nz

reframing diagnosis.



Graeme Sinclair is well known for his popular TV series Gone Fishin. He has been attending Neurophysics Therapy Clinic and is interviewed here by Therapist, Jane Matthews.

Graeme Sinclair has lived with multiple sclerosis since the late 90s and he would like to see the attitude towards treatment and management of the condition change.

"We should say to newly-diagnosed patients that it's a severe challenge, and we're going to have to work together," he says. He understands there are several courses MS can take, but he for one always refused to believe in the course of the disease was going to limit him.

"If I'd believed what I was first told, I'd be tired, depressed, out of work, broke and in a chair," he says. *"Well, only one of those things is true – and I'm working on that one too!"*

Since his diagnosis, he has made 19 more series of his show Gone Fishin, met and fallen in love with his wonderful wife Sandee and is father to James and Amelia. *"I'm actually happy with what this disease gave me,"* he says. *"I'd always been incredibly driven – I've learned to be easier on myself. It's life changing but not all bad. I've had*

to address some lifestyle factors. But, surround yourself with positive people, show people how to help you, and display enthusiasm for life, and there is a chance to reverse the effects deemed irreversible."

Insurance brokers, ironically, have introduced Graeme to two of his most successful paths of treatment. The first introduced him to Matt Tizard, who has been instrumental in keeping Graeme healthy for some years, and the second put him in contact with NeuroPhysics Therapy, which he has been practicing for the past year at the Energy N Motion centre in Grey Lynn, Auckland.

Since completing the intensive programme and continuing to build on the results he achieved there with regular practice, Graeme has *"sensation right down to my feet, more movement, more strength, more control, better balance and accruing positivity."* NeuroPhysics Therapy establishes strong, functional neural pathways and ideal posture, leading to a robust, healthy overall system rather than treating people as collection of individual parts or "a condition."

"I want to get more mobility back," he says. *"It's going to take discipline, but I want to make use of what I have achieved so far and go further."*

The fact that Graeme is currently in a wheelchair has barely slowed him down at all. His energy is infectious and he is constantly looking for the fun and good in life and people. He still travels the length of the country regularly filming and fishing - the great outdoors has always been medicinal to him. ***"Fiordland is a medicinal spot,"*** he says. ***"It's just so awe-inspiring."***

His son James has also inherited his father's love of all things outdoorsy, and is Graeme's P.A. - his 'Pack Animal,' lending a hand with driving, mobility and other tasks. It seems like a win-win - there's plenty of cheek between the two of them, along with tons of love and respect.

Graeme urges people to reframe their MS diagnosis - there are absolutely steps you can take to help yourself - ***"grab them and embrace them"***, he says.

Neurophysics Therapy Clinic is offering a half price initial consultation to member of MS Auckland. Just mention this article when you book.

Neurophysics Therapy Clinic is located at:
Unit 5, 318 Richmond Road, Grey Lynn
Phone 361 3516
E-mail greylynn@neurophysicstherapy.global



Graeme with Therapists Jane and Ollie

OMS retreats for 2017.

The Gawler Foundation located at the beautiful Yarra Valley Living Centre in Victoria, Australia, will be holding 2 Overcoming Multiple Sclerosis retreats in 2017.

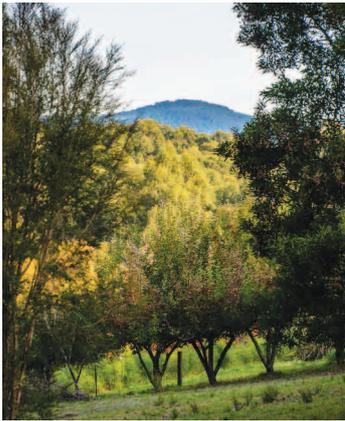
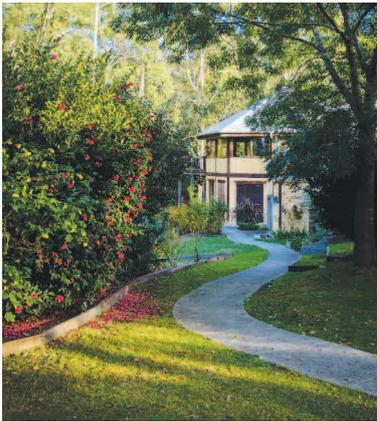
The dates of these retreats will be:

- 8-12 May 2017
- 13-17 November 2017

These retreats are very popular.

“ I went to the program feeling broken and was given the tools to put myself back together - Karen Law ”

For more information and to register your interest go to: <http://gawler.org/retreats-and-services/overcoming-multiple-sclerosis/> or e-mail info@gawler.org



Carolyn's team



Suzie & Ingrid

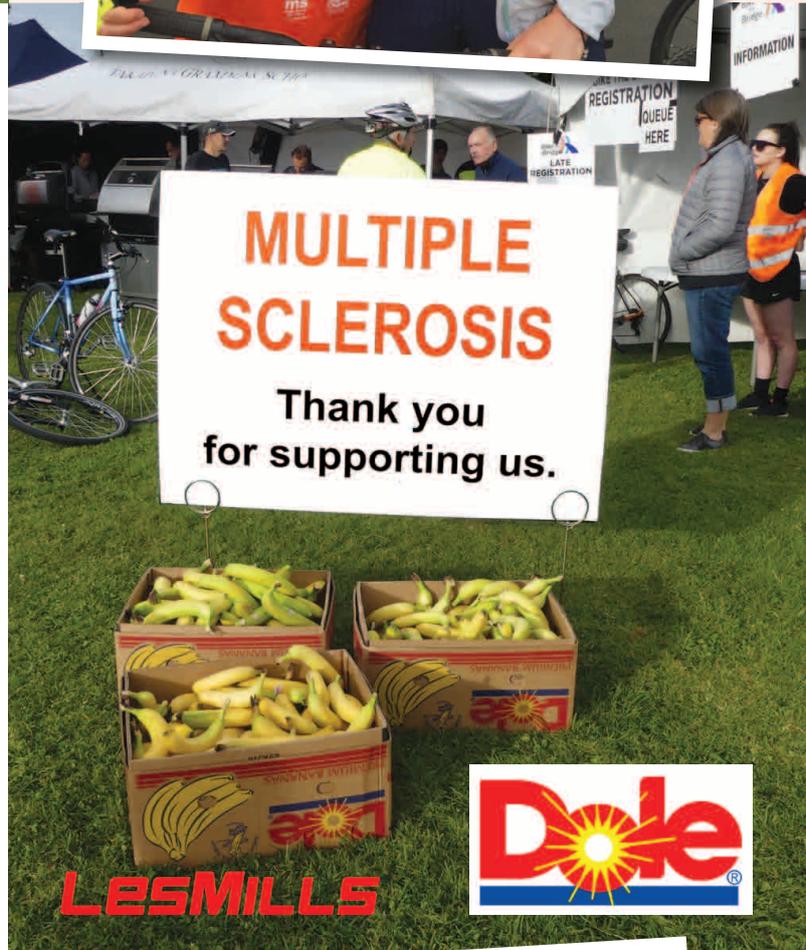


Sunday the 13th of November was Bike the Bridge. About 3500 people came out early on a sunny Auckland morning to bike over the Auckland Harbour Bridge. Such a fun morning! A big thank you to Callum McNair and his team for another successful event. We so appreciate being the dedicated charity for this fun, family event, now in its 5th year. It raises both awareness and much needed funding for MS Auckland services.

Thank you also to Dole for supplying us with 4,000 bananas to hand out - they were very much appreciated by hungry and tired riders and their supporters - and Les Mills for the spot prizes of free gym sessions and membership.

Thank you to everyone who came out to ride, to everyone who donated, and everyone who volunteered and helped with the event. We hope to be able to announce the final total amount of funds raised over the next few weeks.

We look forward to seeing you there next year!!



Judith handing out the medals



book review.

Unexpected Rewards

Travelling to the Arctic with a mobility scooter by
Maureen T Corrigan

This is a very detailed account of one of the many trips Maureen and her friend and flatmate, Sue, have taken since Maureen's diagnosis of Multiple Sclerosis over 20 years ago.

Maureen was a Medical Practitioner and CEO working in Healthcare. She has a very positive attitude and now follows her dreams and passions.

Her motto is: be prepared.

This book is about the planning prior to, as well as the challenges and rewards of a trip to Norway and the Arctic Circle.

Because Maureen is on 4 weekly infusions of Tysabri, her time abroad is limited. Though there is some flexibility, her trips usually last around 25 days.

Maureen always travels with a companion and uses her new, trusty scooter, as well as a walking stick for mobility. Sue helps locate the scooter after flights, lifts it over obstacles, folds it away and the two of them manage to place it in car boots when necessary.

She has outlined details of what she looks for on her expeditions in order to make them a reality. For example: when travelling by ship or ferry – Does the gangplank accommodate a scooter in order to board? Does the ship have an elevator between floors? Can she manage to embark or disembark to and from smaller excursion boats in order to explore?

Half way down pages 61 and into 62, Maureen shares travel hints on the required paper work and protection for her scooter's lithium batteries on flights. Page 244 offers advice on what obstacles and predicaments can occur while travelling with mobility devices.

When planning their exploits both Maureen and Sue want to travel to destinations somewhat unusual with an element of remoteness and "an edge".

This book is about Norway and Spitsbergen Island in the Svalbard Arctic region, which was chosen because of its remoteness and in the hope of seeing Polar Bears. This tour included a side trip to Flåm, meaning



Carolin reading Unexpected Rewards

Maureen had to assess the viability of travelling by bus, ferry and train along with the accessibility of the local hotels, while explaining the difficulties of her situation to foreign contacts, whom occasionally communicated with limited English.

All stops along the way offered challenges in different ways. Oslo had few disability ramps or lifts but had many stairs. The city also had very uneven terrain, such as numerous paving gutters and bumps for her scooter to negotiate.

Though there are few photos, her travel-log describes the sites, museums, activities and cities she visits. In addition, she includes individual passages of the challenges for specific symptoms that she must face and find coping mechanisms for. For example: on page 222 she includes a section on bladder urgency and incontinence.

Maureen follows the dietary advice of Dr Rosemary Stanton – PhD in Nutrition. Strict diets can add another hurdle when making travel plans.

In conclusion, this book gives a real insight into the complications that any travel incurs for someone who is less able bodied. Both Maureen and Sue had a most enjoyable trip to Norway with many adventures along the way. Generally the experience unfolded smoothly because of the preparation and organisation that Maureen accomplished, prior to leaving.

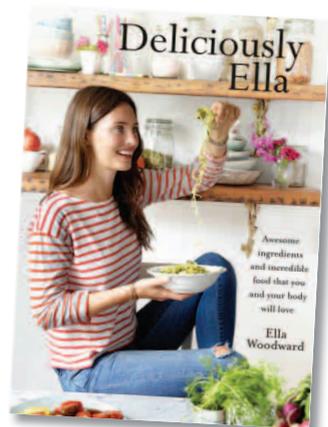
"I keep travelling because I love it and because I want to see as much as I can. I'm going to keep giving it a go and my best shot."

food & recipe.



We were delighted to receive 3 copies of the wonderful Deliciously Ella Cookbook for our library, donated by our lovely Suzie. The book is being used quite a bit by the office staff and we all have our favourite recipes already from it.

Suzie was fortunate enough to meet Ella recently. She writes: *"I was so thrilled to meet Deliciously Ella at the Wimbledon Literary Festival during my recent trip to the UK and thank her for being such an inspiration when I was starting the Jelinek diet. Her recipes are really tasty and about 85% of them are Jelinek-friendly. Ella is on Instagram and facebook and she also has a website (www.deliciouslyella.com) with lots of great recipes."*



We asked Suzie what recipe from the book is her favourite. She provided the following simple dessert recipe with the comment:

"I love this dessert as it's so simple to make yet feels indulgent and is still Jelinek-friendly. I usually use Cacao powder instead of the chocolate though and sometimes use raisins instead of dates. As a special treat I add Cointreau. If I'm going to someone's house for a meal, I'll make this in a dish and just cook it with a tinfoil lid over the top. I cut the bananas in half lengthwise to fit them into the dish better. My friends love it."

Baked Bananas Recipe - Serves 4

Ingredients

4 very ripe bananas
1 teaspoon ground cinnamon
4 Medjool dates
60g chocolate (I use raw chocolate, which only uses coconut sugar, but dark chocolate works too)

Instructions:

Preheat the oven to 200 degrees Celsius

1. Slice each banana in half without going all the way to the bottom, so that they are still whole. Place each banana on its own sheet of tin foil, which needs to be big enough to totally wrap round it and seal it.
2. Sprinkle the cinnamon into the split of the four bananas, sharing it even among them.
3. Remove the stones and cut up the dates, then put the pieces on top of the cinnamon.
4. Finally break up the chocolate and spread it evenly on top of the dates.
5. Wrap the foil around each banana and bake for 10 minutes until the chocolate has melted and the bananas are deliciously soft.



If you haven't checked out our extensive library yet go to - <http://www.msakl.org.nz/library>. All books are available to be borrowed by members.

MS pain and medicinal cannabis.

RESEARCH



By Ingrid Minett

I met Dr Huhana Hickey (fondly known as Dr Hu) and her dog Finn outside her Papatoetoe home on a sunny morning. Hu is the first person in New Zealand to be prescribed Tilray, the cheaper alternative to the approved medicinal cannabis preparation, Sativex. I confessed my ignorance to her on medicinal cannabis. She patiently told me about her experiences and in the process I learnt a lot about this lovely person.

Huhana was diagnosed with primary progressive MS in 2010 after a car accident when she was given an MRI. She recalls the doctor saying “the good news is you don’t have whiplash – the bad news is you have MS”. They found the lesions on her neck. She had been having MS symptoms since 1991, so wasn’t surprised, but was never tested for MS, even with many of the tell tale signs. She thinks it may be because of her Maori heritage (on her Mother’s side, her Father being Sami – from the Norway, Sweden, Finland region). MS is very uncommon in Maori. She remembers Dr Ernie Willoughby being outraged that she hadn’t been diagnosed earlier. An earlier diagnosis may have seen a much different progression of the MS for her.

The worst thing for Huhana was the chronic pain. “Not normal pain”, she says, “but the hyper sensitive pain, that is there and gets worse with just being touched”. She speaks highly of her neurologist Dr Jennifer Periera, who referred her to a wonderful pain specialist. “I was on a cocktail of opiates like morphine, codeine and tramadol”, she says “and I still felt awful and had severe pain”.



Hu and Finn

Huhana started on Sativex in February 2016. She first had to wean off the addictive opiates she was being prescribed to be able to start clean. It took 10 days for the Sativex to start working – which made Huhana wonder if she had done the

right thing. At \$1,200 for a months supply (through the hospital pharmacy – it would have been \$1,500 at the chemist), it is quite an investment. Huhana went into her kiwisaver to cover the expense.

After about 10 days she started to feel normal again. “I still have pain”, she says, “but normal pain”. Some pain is okay. You need to learn to make pain your friend”. For the first time in a long time Huhana felt alive again. She had more clarity of thought. She could function better at work. And her cocktail of daily pills reduced from up to 70 to just 12.

Sativex is in a spray form that you apply under your tongue. Huhana started with a full dose, morning and night. Now she only has half a dose and takes it in the evening. It settles the spasms and the pain and gives her a good night’s sleep.

Sativex can be prescribed to patients who have not responded to other medication, or who suffer intolerable side effects from them. However it is prohibitively expensive for most people. Tilray, which comes from Canada, will likely cost less than half and save Huhana about \$700 a month.

When we met she was still waiting for the Tilray to arrive, and expected it by the end of November. It is a liquid droplet instead of a spray. Huhana will be working closely with her pain specialist to monitor it and ensure she is on the right dosage. It is important for Huhana to work within the law and to do things correctly.

Huhana’s application was supported by Shane Le Brun, from Medical Cannabis Awareness NZ. She recommends anyone interested in Sativex or Tilray to contact Shane through their website (<http://mcaawarenessnz.org/>), or Facebook page.

Huhana will do a vlog (video blog) once she starts Tilray, for anyone interested in following her developments. We will be watching it with interest. I left our meeting grateful to have met Hu - a remarkable and gifted person with an energy and enthusiasm for life that is infectious.

Huhana welcomes questions about Sativex or Tilray and can be e-mailed at: huhana@gmail.com.

clinically stable MS and magnetic resonance imaging.

The following article was written by Brett Drummond, MS researcher and Science communicator, from MStranlate. You can find the complete article here <http://www.mstranlate.com.au/>

What is clinically stable multiple sclerosis?

As most of you might be aware, the most common form of multiple sclerosis is relapsing-remitting MS (RRMS). In RRMS, people may go through periods of attacks (called relapses) or periods of remission (where the disease does not appear to be progressing). The times of remission can vary. Increasingly, with new medications, people can have extended periods of remission. During these periods, they often find that they don't develop new symptoms and their existing ones stay the same. This is referred to as clinically stable MS.

What is magnetic resonance imaging (MRI)?

Magnetic resonance imaging or MRI is an imaging technique that is useful for collecting pictures of organs and tissues, such as the brain. MRI is used as a tool in MS for diagnosis, monitoring disease progress and measuring the success of treatments. It allows for the detection of lesions (area of myelin damage) in the central nervous system, however, only those that occur in white matter. It has been recently shown that many lesions occur in the grey matter and that current MRI techniques cannot detect these.

Should clinically stable individuals get regular MRI scans?

It has been routine neurological practice to continue to obtain MRI images for people with MS, even those that are clinically stable. It is thought that this is useful, as 'silent' damage can still be occurring in these individuals – that is, new damage to the myelin without any signs or symptoms. However, very few studies have been done to provide evidence for this.

Recently, a study was performed by researchers from the Providence Brain and Spine Institute to investigate this question. Using collected data, they analysed the data from 436 people with clinically stable MS who had regular MRI scans over a 2-3 year period. In this, they found that 16.7% did have changes on their MRI scans – either as new, enhancing or enlarged lesions. In this group, 26% (4.4% of the total group) changed their medication based on the differences observed on their MRI images.

This information could be viewed in one of two ways. Firstly (as the authors did), it could be concluded that this provides evidence that disease activity can still be occurring in people with clinically stable MS, meaning the use of regular MRI scans is justified and necessary to ensure their best outcomes.

On the other hand, the low numbers of people with clinically stable MS that had changes on their MRI, combined with the fact that even this very rarely resulted in any changes in treatment plan, could be used as a reason to argue against regular scanning.

It should be noted that this data was obtained using either a 1.5T or a 3.0T MRI. These less sensitive scans may have missed some disease activity, which would affect the overall results. These results must also be viewed in the context of research into the safety of MRI contrast agent, gadolinium, which has been found to remain deposited in brain tissue. The long-term safety implications of this are still unknown.

The pros and cons of having regular MRI scans should be discussed with your neurologist. A clear plan should be established as to why the scans are being performed and what action will be taken if changes do appear in the images.

To learn more about MStranlate, visit their website www.mstranlate.com.au



the MS nurses at Auckland hospital.

The MS nursing office is running a reduced service over the Christmas period and into January.

A 3 day per week service of Monday, Thursday and Friday will be available. However the office will be shut to observe statutory holidays.

Should you be experiencing an MS relapse or increased symptoms over this time please inform us but also speak to your GP so your concerns can be addressed as quickly as possible.

Ensuring your prescriptions are up to date via your GP surgery before Christmas will make for a less stressful holiday. Please note that we will not be able to provide urgent prescriptions over this time if your GP is shut.

We ask that you please do not leave non-urgent phone messages during the Christmas period.



Fiona and Nazila

Please call back with non-urgent queries after the 9th of January.

Have a wonderful summer.
Nazila and Fiona

Contact

e-mail - MSNurse@adhb.govt.nz
Phone: 09 307 4949 ext. 25885#

Leaving a gift in your Will
is an easy way to support us.

include *a charity*
Help the work live on.



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Many everyday people like to leave a gift in their Will. The truth is that most gifts are made by ordinary, hardworking people who want to give lasting support to causes that are important in their lives. The good news is that including a charity in your Will is just as easy as providing for your loved ones. And it can be as much or as little as you want.

Without the generosity of everyday Kiwis, the services Multiple Sclerosis Auckland provides wouldn't exist. Supporting us in this way is essential for ensuring our work continues into the future.

If you would like further information about writing a Will or leaving a gift to Multiple Sclerosis Auckland, or for a confidential no-obligation chat about how your gift can make a difference please contact Mark or Ingrid on (09) 845 5921, or by e-mail on mark@msakl.org.nz or Ingrid@msakl.org.nz.

support groups.

Location	Contact	Date/ Time
South / East Auckland		
Beachlands Support Group Pepper Jacks Café	Dianne Bartlett 021 845 903	Fridays / Six Weekly 11.30am
Pukekohe Café Group Different Venues	Dianne Bartlett 021 845 903	First Thursday / Month 11.30am
Botany Café Group Whitcoulls Coffee Lounge (Botany Town Centre)	Dianne Bartlett 021 845 903	Third Thursday / Month 11.30am
Mangere Support Group Hollywood Café (Mangere Town Centre)	Dianne Bartlett 021 845 903	Second Monday / Month 10.30am
Manukau Café Group Friendship House (Manukau)	Dianne Bartlett 021 845 903	Last Tuesday / Month 10.30am
Central		
City Evening Group Scarecrow Café	Carol Andrews 021 959 187	Wednesday / Six Weekly 6.00pm
Cornwall Park Walking Group Cornwall Park	Carol Andrews 021 959 187	Tuesday / Weekly 10.00am
Greenlane Café Group Mama Rich Café (205 Great South Rd, Greenlane)	Carol Andrews 021 959 187	Second Saturday / Month 11.00am
Stonefields Café Group Stonebake Café (Lunn Avenue, Mt Wellington)	Carol Andrews 021 959 187	Third Wednesday / Month 10.30am
Onehunga Group Frolic Café (Manukau Rd, Royal Oak)	Carol Andrews 021 959 187	Second Tuesday / Month 10.30am
West Auckland & Rodney		
Kumeu Café Group Different Venues	Andrea Kortas 021 959 189	First Tuesday / Month 10.30am
Henderson Garden Café Group Espresso Garden Café (inside Mitre 10 Mega, 186 Lincoln Rd)	Andrea Kortas 021 959 189	First Thursday / Month 11.00am
North Café Groupies Kings Plant Barn (Silverdale)	Andrea Kortas 021 959 189	Third Wednesday / Month 10.30am
North Auckland		
Mayfield Coffee Morning Kings Plant Barn (Porana Rd, Glenfield)	Diane Hampton 021 859 187	First Thursday / Month 10.30am
Shore Lunch Group Palmer's Planet Café (cnr Hugh Green Drive/Greville Rd, Albany)	Diane Hampton 021 859 187	Last Wednesday / Bimonthly 12.00 noon
North Shore Café Group Kings Plant Barn (Porana Road, Glenfield)	Christine Ball 09 444 6945	First Saturday / Month 12.30pm

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Gilenya[®] (fingolimod) 0.5mg is a prescription medicine available as capsules for the treatment of patients with relapsing multiple sclerosis to reduce the frequency of relapses and to delay the progression of disability. Gilenya is a fully funded medicine under Special Authority Criteria. Normal doctor visit fees and prescription charges apply. Out-patient monitoring will be necessary for administering the first dose. You should avoid becoming pregnant while taking Gilenya and for two months after you stop taking it. It is important not to stop taking this medicine without your doctor's advice. Gilenya has risks and benefits. Cautions are infections, vaccinations, visual disturbances, decrease in heart rate, signs of liver disorders, sudden onset of severe headache, nausea, and vomiting, pearly nodules, patches or open sores of the skin. Talk to your doctor right away if you experience any of these, or experience worsening of your MS symptoms. Side effects can include headache, liver enzyme increased, diarrhoea, cough, influenza, sinusitis, and back pain. Refer to consumer medicine information at the website www.medsafe.govt.nz for full details. Ask your doctor if Gilenya is right for you. Use strictly as directed. If symptoms continue or you need further information or you have side effects see your doctor. Gilenya is the registered trademark of Novartis AG. Novartis New Zealand Ltd, Auckland.

References: 1. Gilenya Consumer Medicine Information available at www.medsafe.govt.nz 2. Pharmaceutical Schedule available at www.pharmac.health.nz



Membership and/ or Donation Form.

ms.

**Multiple Sclerosis
AUCKLAND**

www.msakl.org.nz

Please return this form to: Multiple Sclerosis Auckland
PO Box 33574, Takapuna, Auckland 0740
Email: info@msakl.org.nz, Telephone: 09 845 5921

First Name: _____

Date: ____ / ____ / ____

Surname: _____

Email: _____

Address: _____

Home ph: _____

Work ph: _____

_____ Post code _____

Mobile: _____

Membership Information

Date of birth: ____ / ____ / ____

Is this a renewal membership? Yes: No:

Membership No. _____

Please select one of the following:

Membership Type:

I have MS

Annual Individual \$40

A family member has MS

Annual Individual Beneficiary \$20

Supporter

Annual Family \$55

I am a health professional

Lifetime Individual \$400

Other _____

Lifetime Family \$550

For an Annual or Lifetime Family Membership, please give details of the family members you wish to include:

Name: _____ Address: _____ Email: _____ Phone: _____ Mobile: _____

1 _____

2 _____

3 _____

I wish to give a donation: \$10 \$20 \$50 \$100 Other \$ _____

Total Payment to MS Auckland

Membership: \$ _____ Donation: \$ _____ **TOTAL \$** _____

Payment Options: Visa or Mastercard Expiry Date ____ / ____ Name on card: _____

Card Number

I have enclosed my cheque payment of \$ _____ Please make cheques payable to Multiple Sclerosis Auckland.

Deposited into MS Account No. **12 3047 0088939 00** ASB Bank. (Please use your first and last name as reference)

I give my approval for my photo to be used in any of MS Auckland's publications: Signature: _____

our supporters.

MS Auckland is grateful to all organisations, families and individuals who support our work. Key supporters over the past year:



A complete list of all our supporters is available in our Annual Report.

Special thanks also to our wonderful volunteers who give us their time, expertise and support.



Takapuna Community Services Building
Top Floor, 5 The Strand, Takapuna, Auckland 0622
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TECFIDERA[®] (dimethyl fumarate) is a Prescription Medicine containing 120 mg or 240 mg dimethyl fumarate in a modified release capsule for oral use. **Approved Use:** TECFIDERA is used for the treatment of patients with relapsing remitting multiple sclerosis (MS) to reduce the frequency of relapse and delay the progression of disability. Do not take TECFIDERA if you have any allergy to dimethyl fumarate or any ingredients listed in the Consumer Medicine Information. Like all medicines, TECFIDERA has risks and benefits. Ask your doctor if TECFIDERA is right for you. Use strictly as directed. If your symptoms continue or you have side effects, see your doctor, MS nurse or other health professional. **Side Effects:** Very common side effects include: flushing, diarrhea, nausea, stomach pain or cramps. Common side effects include: gastroenteritis, low white blood cell counts (lymphopenia, leucopaenia), burning sensation, hot flush, vomiting, indigestion (dyspepsia), gastritis, gastrointestinal disorder, itchy skin (pruritis), rash, pink or red skin (erythema), feeling hot, protein (albumin) present in urine, increased liver enzymes (aspartate aminotransferase and alanine aminotransferase) and white blood cell count decreased. Serious side effects include: signs of an infection. Serious side effects are rare. **Further Information:** For further information see the TECFIDERA Consumer Medicine Information (CMI) available at www.medsafe.govt.nz or by calling 0800 852 289. Biogen NZ Ltd, 54 Carbine Road, Mt Wellington, Auckland.

References: 1. TECFIDERA Data Sheet [18 Nov 2015]. 2. PHARMAC website – www.pharmac.govt.nz. Date accessed 4th February 2016. TECFIDERA is a funded medicine – a pharmacy charge and Special Authority criteria will apply. Normal doctors' charges will apply.


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