

multiple news

Multiple Sclerosis Auckland Magazine

March 2017 | Issue 36

Rick Dodson – living life to the fullest

inside

change is
in the air

exercise & ms

food & recipe

stem cell research

and more...





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 and MRI lesions.

Aubagio, working to help quiet MS.*

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


(teriflunomide) 14 mg tablets

*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.

AUBAGIO® (teriflunomide, 14 mg tablets) is a Prescription Medicine for the treatment of patients with relapsing forms of Multiple Sclerosis to reduce the frequency of clinical relapses and to delay the progression of physical disability. AUBAGIO has risks and benefits. For more information read the Consumer Medicines Information available at www.medsafe.govt.nz. Ask your doctor if AUBAGIO is right for you. Use strictly as directed. If symptoms continue, or you have side effects, see your doctor. AUBAGIO is a fully funded medicine. Special authority criteria apply. Normal doctors visit fees apply. References: Aubagio Approved Data Sheet November 2016. Additional references to support the information in this advertisement are available on request. Sanofi New Zealand. Level 8, 56 Cawley Street, Ellerslie, Auckland. GZANZ.AUBA.16.02.0009. February 2017. GEAB12114. TAPS MR5167.

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our people.

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For more information visit www.msakl.org.nz

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a few words from Ingrid.

Our General Manager

Hello again! It seemed like just the other day I was sitting down and writing a few words for our December magazine. Is it just me, or has this year gone crazy fast? I hope the start of the year has been good to you, and you that you have been able to embrace the last of the summer weather.

There is always a lot happening at MS Auckland. We've made a few improvements to the way people can join us. We hope it will see more people opting to be a part of the community and take advantage of what we have to offer, or contribute to our work. You can read all about it in this magazine.

MS Auckland is all about the people, the people, the people. Rick Dodson is this editions inspiring cover story. As a member of the Kiwi Gold Sailing team, he's an inspiration to others living with MS. While their dream of winning a medal was not realized, they had a very successful 4 years, and a very exciting finish in Rio.

Unfortunately I have just received the news that sailing will not be included as a sport for the 2020 Paralympics. Needless to say this has shocked and disappointed the worldwide sailing community.

Andrew Coe was chosen this quarter for our profile on volunteers, which I was thrilled about. When he comes into the office he is like a breath of fresh air! He is willing to give a hand wherever it is needed and is always smiling and so positive. During the school holidays he also brings in his beautiful girls to help, making giving to the community very much a family affair.

We welcomed Tessa to our team in February, who has joined us on an Internship to assist with our projects and events. She has jumped in with both feet and is already making a great impact.

Our Committee member, Graham Wear, talks openly to us of his son Steven, who had MS and sadly passed away. Graham and Judy have made a decision to remember Steven through a gift to MS Auckland in their Will. MS Auckland has been able to exist and carry out its good work over the past 51 years because of the kindness and generosity of people such as the Wear family.

Fundraising continues to be essential for our operations. This year's mid-year event will be bigger than ever before as we get in with the British Lions Rugby Tour for a gala dinner and auction event. Read more about it in this magazine and check out the website www.coth4ms.com.

Just a reminder, while this magazine comes out quarterly we also have a brief e-newsletter that is distributed monthly. If you are not getting your e-newsletter please go to our website – www.msakl.org.nz and sign up.

Until next time, wishing you all the best
Ingrid



Rick – a positive role model in this young girls' life

| | | |
|---|--|---|
| MS Auckland office is located at 5 The Strand, Takapuna | Phone number: 09 845 5921 | info@msakl.org.nz |
| Office Hours Monday – Friday 9am to 5pm | e-mail addresses: Ingrid@msakl.org.nz Mark@msakl.org.nz | Kirsty@msakl.org.nz Becky@msakl.org.nz |

events for your calendar.



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|--|---|---|---|
| 25th March Brain Day 9:30 to 3pm University of Auckland Business School, Owen G Glenn Building, 12 Grafton Road Cost – Free www.brainweek.co.nz | 1st April Research Day 9:45am – 2:45pm Alexandra Park, Epsom (See page 16) | 12th April MS Auckland AGM (See page 17) | 6th May Wellness Workshop More details will be available in April |
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change is in the air.

Change can make us all feel a bit uneasy. It can take us out of our comfort zone and what we are familiar with, to new and unexplored territory, and that can be scary! I'm reminded of a quote 'The world hates change, yet it is the only thing that has brought progress'.

There are a few changes to the way MS Auckland is approaching membership this year. For many years membership to MS Auckland has been through a set fee structure. We are exploring moving to 'joining by donation', as opposed to 'joining by fee'. The main reason for the change is that MS Auckland would like to always be open to all people and their families living with MS. While this has always been the case there seemed to be a perception in the community that people had to be a 'member' to access our services.

People who join by donation will enjoy all the services and support that MS Auckland offers. Because we are an incorporated society the only thing that joining by donation currently will not allow is voting at AGMs. Rest assured though that your feedback and your voice on our work will always be heard and is very important to us. Joining by donation will have the added benefit of being eligible for a tax receipt.

The Incorporated Societies Act 1908 is now more than 100 years old and needs updating to help govern and administer societies in today's world. The Ministry has been consulting on changes and we expect to have an updated Act by next year.

When the new Act is revealed the MS Auckland Committee will look at it and may go to the members to see if they wish that MS Auckland remain an Incorporated Society or if they would like to consider another structure.

If you currently pay a set annual membership fee than you may continue without any changes. If you are new to MS Auckland then we invite you to join us by donation – any amount that you feel you would like to give. We would like to encourage people to consider regular giving, through an automatic payment set up through your bank. This will ensure that you are always a 'donating member'. You will receive a tax receipt for your donations at the end of the financial year. Alternatively you may choose to give a one off donation each year.

Even if you do not currently require the services of MS, or even if you don't personally have MS, we hope you will consider being part of the MS Auckland Community. This will help us in continuing to fund our services as well as helping us with our advocacy work for improving access to treatment and services for people with MS. It is the kindness and generosity of many people over the past 51 years that has enabled MS Auckland to continue to serve the MS community.

If you have any questions/comments on the changes to joining MS Auckland, we would love to hear from you. Please e-mail Ingrid@msakl.org.nz or call us on 09 845 5921 and ask to speak to Ingrid.

from the field.

Field Worker Carol Andrews highlights the benefits of Support Groups in this article.

Support Groups

Support Groups are groups of people who gather to share common problems and experiences associated with a particular, condition, illness, or personal circumstances.

In a support group, you are able to talk to other people who truly understand what you are going through, can offer emotional support and share the type of practical insights than can only come from first-hand experience.

Benefits:

- A support group is a safe place to talk about worries, issues, experiences, struggles and thoughts
- Realising you are not alone, there are other people who have the same concerns and problems
- Members who have the same problems can support each other and may suggest new ways of dealing with a particular problem
- Socialisation. A chance to meet new people in a similar situation as yourself
- Members can share ideas and knowledge and keep one another up to date with news of interest to them
- Talking to others in the group can help reduce anxiety



Carol
Central
Auckland

Dianne
South
Auckland

Andrea
West
Auckland

Diane
North
Shore

What to expect in a Support Group

Most of our support groups are made up of between 5-10 members who meet once a month, either at someone's home or in a local café.

Each meeting lasts around 1-1½ hours and most are facilitated by a Field Worker, although several of our longer standing groups are now peer led and organised. Everything that is discussed in the group is confidential and everyone is given the chance to speak.

We presently have 16 support groups running throughout Auckland and welcome any new members. You will find a full list of current groups on page 20. If you would like more information on any of the groups or are interested in having a Support Group in your area or leading a group, please contact the Field Worker serving your area.



The 'North Café Groupies' Support Group enjoying their end of year Christmas lunch.

from the MS nurses.



It seems like 2017 is off to a flying start. The New Year is the perfect time for feeling like we are organising our lives for the 12 months ahead. So to help with this, here are a few pointers for a stress-free year with your medications.

Your GP is the only person to ask about on-going prescriptions. If you start a new medicine when you visit your neurologist your GP will be informed of the name and dose for on-going prescribing. Prescriptions are valid in New Zealand for 3 months only and three months can race by. Contacting your GP for repeat prescriptions as soon as you collect the last repeat supply of your medicine can help avoid the last minute stress we all feel when the realisation dawns that you have one tablet left.

If you are someone who is taking the PHARMAC subsidised medications you will have received communication from PHARMAC reminding you of when you need to see your neurologists again for a review. We encourage you to make note of this date in your diary and make contact with the ADHB neurology bookings team on (09) 307 4949 extn 25820 the month before this is due to make sure your booking has been processed.

Due to the nature of the Auckland Hospital neurology department the roster is only available 6 weeks in advance. The neurologists, although based at Auckland

Hospital also cover North Shore Greenlane, and Middlemore Hospital(s) and the Manukau Superclinic. This results in you often receiving relatively short notice for appointments. We realise that this can be majorly stressful. However without the annual review PHARMAC can't renew your special authority number. Without a current special authority number your pharmacist can't dispense your medicine. An idea of when you should be reviewed will help you negotiate time away from work or family responsibilities and if necessary time to arrange for transport to the appointment.

We look forward to seeing you when you visit your neurologist. Remember that your neurologist has 25 minutes to fit in your review. Please have a think about your major concerns, worries, and symptoms before you arrive. If you have a long list of issues to discuss please let us know by email or phone before your appointment. Where possible we will book an additional 25 minutes to see you to discuss and address your concerns. After investing the time to attend your appointment we want you to get the most out of your visit so that you leave feeling like you have been listened to and involved in decisions about your care.

Is everyone feeling organised yet? If so... lets really push the boat out here! Why not be a master of organisation and chase up your GP to arrange your mammogram, cervical smear, prostate check and all those other lovely checks we look forward to. Do this now and you are sorted for 2017.

Go on, there's your challenge for March! Take care and see you soon Fiona and Nazila.

Multiple Sclerosis Nurse Specialists
Auckland City Hospital
(09) 307 4949 extn 25885

welcome to Tessa.

New project and events intern at MS Auckland.



In 2016 I graduated from AUT University with a bachelor of International Hospitality Management. During my time studying I become particularly interested in event planning and organising, so when an opportunity for an internship at MS Auckland arose, working as a project assistant for events, it seemed like the perfect fit.

I am extremely happy to working for an organisation who make a difference in so many people's lives. I have a visual impairment which means I can empathise with those who face daily challenges and live with uncertainty, I have first-hand experience with just how valuable organisations such as MS Auckland are to those they support and I am extremely grateful I have been given the opportunity to be a part of it.

exercise and MS.

Welcome to 2017!

We understand the challenges of MS are real. Becoming and staying active can be challenging. Given it may be a New Year resolution of yours here are some ways to overcome possible barriers to getting active again!

If you experience MS related fatigue -

- Start slowly - be kind to yourself. Remember it may be tiring at the time but it will energise you in the long run. There are lots of studies that demonstrate the benefits of exercise for people with MS
- Do rest afterward. The main principles are to work your muscles until they are slightly fatigued. Then let your body rest and recover

If you are affected by heat sensitivity - when very small increases in core body temperature can lead to increases in symptom severity -

- Pre-cooling the body prior to exercise has been shown to reduce the effects of heat sensitivity
- Researchers in South Australia have also been conducting a clinical trial into the use of cooling vests during exercise
- Alternatively try to position yourself near an open window or fan

You don't need to join a gym -

- Try walking further between your destinations
- Try an exercise video at home
- Walk or wheel round your neighbourhood
- Team up with a friend and come to a water based session in your region
- The MS Trust's (United Kingdom) series of exercise videos for people with MS can be done in a seated or standing position to address balance, endurance, strength and flexibility

www.mstrust.org.uk/understanding-ms/lifestyle/exercises-people-ms

www.mstrust.org.uk/understanding-ms/living-ms/lifestyle/exercise-and-ms/exercise-videos

If you have chronic pain

- Check with a health professional if it is safe to start or continue exercising. You may want to try different physical activities and types of equipment depending on your painful regions

Exercise can be beneficial in managing symptoms and maintaining overall wellbeing. Studies have shown

Written by Julie Rope, NZRP, Director and Senior Clinical Practitioner, Rope Neuro Rehabilitation Ltd



Left hand side of the table from the front: Larissa, Lauren, Mark, Julie, Barbara. Right hand side from the front: Laura, Sarah, Charlotte, Rachel, Jan and Rachel

that a positive attitude leads to those finding ways to exercise.

Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis produced in 2014 recommend that people with mild to moderate disability from MS should undertake 30 minutes of moderate intensity exercise two times per week, and strength-training exercises for major muscle groups two times per week. The researchers also developed an online MS Get Fit Toolkit, in conjunction with the Canadian MS Society

<http://pace.mcmaster.ca/mstoolkit/>
www.csep.ca/en/guidelines/physical-activity-guidelines-for-special-populations

For those of you who attend the Hydrotherapy group session you will be aware of our 'objective measures sessions' where we aim to capture physical benefit made by regular attendance.

We are aware that benefit is not always measurable by the number of sit to stands you are able to perform the day we are testing. We are hoping to be able to capture the non-visually measurable benefits through questionnaires and conversations across the year to truly capture all the gains made by your attendance.

We look forward to seeing you all keeping physically active across Auckland at the hydrotherapy sessions in your local area.

Julie Rope and the team at Rope Neuro Rehabilitation.

hydrotherapy.

Bonnie Robinson writes about her experience in joining the Hydrotherapy classes at Lloyd Elsmore Pool.

"Late in 2016 I started attending a hydrotherapy class held at Lloyd Elsmore Pool. My motivation was to try and get more strength in my legs, and improve my balance. I've only been going a few weeks but I can tell already that the hydrotherapy is helping.

At the first session I couldn't do some of the exercises very easily but even after 5 sessions I am getting better. I'm finding going to a class is much more motivating than trying to do exercises at home alone, and with the physio leading the group I know I am doing things safely and correctly. Plus being in the water means I don't get too hot (which is a no no for my legs) and I can sustain the exercises for longer – on land I'd fall over pretty quickly!

It is also a place where I can talk about my MS with other people who understand and also just chat to a nice group of friendly people. Some of the people in my class have been attending for a while, but they've been really welcoming of a newbie. If anyone is thinking about attending I'd say – just do it."



Cost

For the MS community the first 2 classes are free – then it is just \$50 for a book of 10.

For people with other neurological conditions the first 2 classes are just \$14 – then it is \$70 for a book of 10.

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

2017 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

sometimes you just don't feel like cooking.

Let's face it, there will be days when you just can't face cooking a meal. There may also be times when cooking becomes too difficult. Finding good wholesome convenience foods can be difficult.

Radix Nutrition provides a wonderful solution. Using advanced technology they are able to deliver convenient packaged meals using 100% natural and, wherever possible, organic, ingredients to the market.

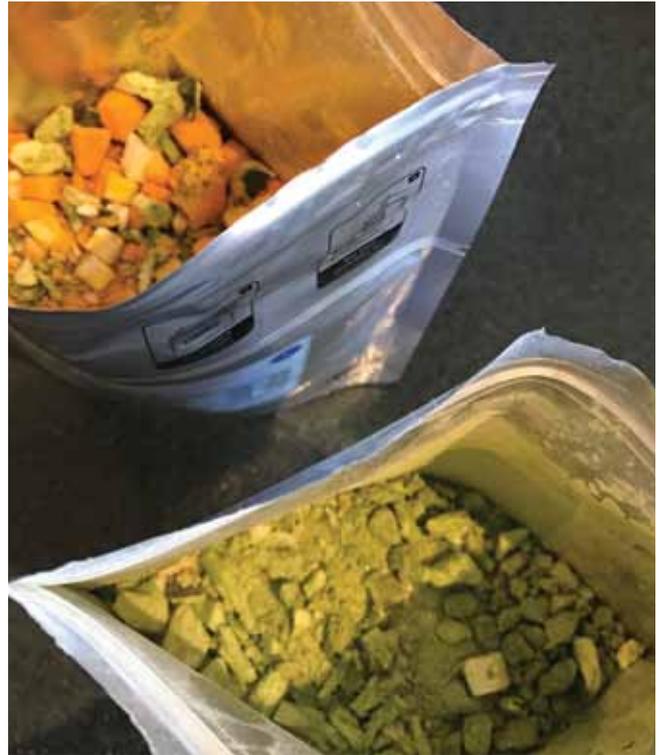
They use a freeze drying method which naturally preserves the nutritional quality of the ingredients. All you need to do is add 350ml (or 1½ cups) of boiling water, stir and wait 10 minutes and serve.

One pack costs \$16 and is a good sized meal for one hungry person. Because we enjoyed it on a Friday evening we also opened a bottle of red wine, making the evening very special. We both loved the meals we had and would certainly look to have more in the pantry for those days when we just don't feel like cooking.



Ingrid preparing dinner

The meals they offer cater for all diet requirements and are for anyone looking for tasty and healthy options. I managed to convince my husband (who loves his home cooked meals) to try some of their products on offer with me. Because we are vegan we tried all 3 of their current vegan friendly meals in their One A Day range – Pea & Mint, Carrot & Coriander and Sweetcorn Chowder.



Before adding the water



Radix Nutrition has offered our readers the chance to win. Three lucky people will win 2 packs each of their choosing. All you have to do is send an e-mail to info@msakl.org.nz with the heading Competition and tell us what 2 packs you would choose to try. Check out the full range of products on offer at <https://radixnutrition.com/>

OMS retreats for 2017.

The Gawler Foundation in Australia is offering only 2 Overcoming Multiple Sclerosis retreats in 2017. The May retreat is already full with a waiting list.

If you are interested in attending the November retreat from the 13th to the 17th of November, you may want to look at booking as soon as possible so as not to miss out.

For more information on the retreat and to register go to: www.gawler.org

food & recipe.

I would like to share with you one of my favourite salads. It is so easy to make, tastes fresh, is nice and filling, and tastes even better the next day for lunch. The recipe comes from a cookbook that we found while visiting Seattle called 'The Accidental Vegan' by Devra Gartenstein. Devra claims that she accidentally fell into the vegan world about ten years ago, and then stuck around for the benefits to her body, her taste buds, and the world around her. It is a great book with lots of good ideas and easy recipes – all vegan of course!



Curried Chickpea Salad

Ingredients

3 cups cooked chickpeas, or 1½ (15 ounce) cans, drained
3 ripe tomatoes, chopped
1 tablespoon chopped fresh mint
1 teaspoon grated ginger
1 tablespoon freshly squeezed lemon juice
1 tablespoon extra-virgin olive oil,
or other oil of your choice (also good oil-free)
1 teaspoon ground cumin
½ teaspoon ground turmeric
½ teaspoon ground cardamom
½ teaspoon ground coriander
1 teaspoon sea salt



Put all the ingredients in a serving bowl and stir until thoroughly combined. Taste and add more salt if you like. Let it stand for at least 10 minutes for the flavours to develop. Serve at room temperature and enjoy!

If you haven't tried chickpeas (also called garbanzo beans), then this can be a good introduction. Chickpeas are an excellent source of protein and fibre as well as being rich in vitamins and minerals. They are so easy to use. You can buy them dried and cook them yourself, if you have the time. This is the most economical way, and I tend to prefer it. I will cook a big batch and then freeze what I don't immediately need for later. You can also purchase tins of chickpeas. If you do this then look for ones without added preservatives or sodium. Ceres is a good reliable brand.

Chickpeas work well in salads because they keep their shape and soak up plenty of flavour. If the spices aren't in your pantry then I highly recommend purchasing them. They are all great spices to have on hand. Turmeric is known to have powerful anti-inflammatory effects and is also a very strong antioxidant. I use all the spices in this recipe a lot in my day to day cooking. However, you could also substitute an equal amount (2½ teaspoons) of curry powder if you prefer.

Just recently when I had an abundance of ripe avocados that needed to be used, and only one tomato, I substituted 2 avocados for 2 of the tomatoes. It was delicious!



Our library includes a number of recipe books, all which are available to be borrowed by members of the MS community. Check out our range of books at: www.msakl.org.nz/library

Rick Dodson's career highlight – sailing for NZ in Rio.

Written by Celia Snedden (Rick's sister)



Rick Dodson was diagnosed with MS the same week Princess Diana was tragically killed, so it makes it easy for him to remember the date - August 1997.

At the time he was a professional yachtsman sailing with Team NZ preparing for their defence of the America's Cup, having also been on the crew when they won it in San Diego in 1995. Due to his symptoms progressing he has been unable to sail professionally since 2010 so was encouraged to team up with David Barnes, ex skipper for Team NZ who also has MS and competed for the 2016 Paralympic games.

Sadly David's symptoms progressed so just a year and a half ago he had to resign from the team. However Rick and his two crew members qualified and were selected for Rio. Contrary to all the reports leading up to Rio, it was a fantastic venue (although tricky sailing conditions), the Brazilian people were extremely friendly and welcoming and Rio 2016 held a wonderful and memorable games.

There were 14 countries competing in the 3 person Sonar class which sailed 11 races over 6 days. The weather varied from very light and fluky to very windy, and it was always difficult to pick the shifts with the mountains towering over the race course.

The kiwi team started the first day with an 8th and a 1st, so felt confident with their boat speed and overall competitiveness. Each day they finished in the top half of the fleet with the top eight boats being extremely close on points.

The Australian team who had been the kiwis' training partners (having travelled to Sydney a few times for training camps), sailed a fantastic regatta, and didn't have to compete in the last race to win the Gold medal. So it was all on for the remaining 8 boats coming into the last race. The NZ team could have won Silver or finished 8th, that is how close the scores were.

The team were winning the last race right up until the end when they were pipped on the finish line by USA who beat them by 1 second to secure the Silver medal. However the kiwis were still holding onto Bronze as the next closest competitor on points was Canada who was back in the fleet with France just ahead of them which should have ensured the Bronze for NZ. But as fate would have it the Canadians pipped the French on the finish line beating them by 1 second making Canada and NZ 3rd equal on points overall. However in yachting you cannot draw for a place so a countback on placings over the regatta was done, which gave Canada the Bronze and NZ 4th place.

Such a close regatta and bittersweet. The NZ crew was ranked 8th coming into the Paralympics, so they could certainly hold their heads high that they performed on the day.

Rick, having won numerous world titles and 2 America's Cups, said Rio was a highlight in his career. "I really enjoyed spending time with the rest of the New Zealand athletes each night back in the kiwi athletes' lounge. What an inspirational group of young people, who don't consider themselves disabled, but acknowledge it is because of their disability that they are there and they are going to make the most of every chance they get. They love life and loved the opportunity of competing in Rio."

Unfortunately Yachting has been dropped from the Tokyo Paralympics so that is the end of that road for Rick. He is constantly looking at new projects to keep his hand in sailing and is hoping to coach the blind sailors.



Celia and Rick



Canadian Paul Tingly giving Rick the Bronze winner mascot

fundraising for MS.



CLASH OF THE HEMISPHERES 2017

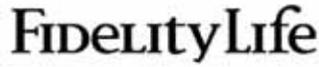
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| | | |
|---|----|---|
| Southern Hemisphere Sir Graham Henry Ian Jones Phil Gifford | VS | Northern Hemisphere Stuart Barnes Miles Harrison Scott Quinnell |
| Referee - Jeremy Corbett | | |







Peter Wood – carer of the year 2016.

Peter Wood was the recipient of the Esme Tombleson Carer of the Year award last year. He was presented with his certificate at our Christmas party by Neil Woodhams, President of MS Auckland, who enlightened us a bit on who Esme Tombleson was.

Esme was a co-founder of the National MS Society and from 1975 she was the President for many years. She was also the founder and president of the Gisborne branch and on the International Federation of the Multiple Sclerosis Society's executive. In 1987 she received the rarely awarded gold medal for distinguished services to Multiple Sclerosis.

Esme was an amazing and dedicated woman and the Carer's award was set up to recognize amazing and dedicated carers and the important role that family members have in the life of a person with MS. All the family members I have met, husbands, wives, parents, children, are wonderful people and all could have been recognized at the event.

Peter stood out this year because of his long involvement and support with MS Auckland and the MS Auckland Region Trust. Maureen, his wife who has MS and is also on the MS Auckland Committee, was thrilled to have her lovely husband recognised, and agrees that he is indeed a very special person.



Neil Woodhams and Peter Wood

More information and support on the role of caring can be found at Carers NZ. This organisation was established by and for family carers. They provide information, advice, learning and support for carers in their network. Check out their website: www.carers.net.nz or call them on (09) 360 7221.

volunteer extraordinaire – Andrew Coe.

Here at MS Auckland we are very lucky to have such a fantastic community of volunteers, helping from hydrotherapy, events, office admin, organising support groups...

This month we would like to acknowledge our 'Jack of all trades' volunteer, Andrew Coe. We have been blessed with Andrew for the last 4 years who continues to support us in every aspect of our society. Always with a smile and a joke, Andrew helps out with office work, events, hydrotherapy and is never afraid to roll up

his sleeves and get dirty! One of the bonuses of his job as a Long Haul Flight Attendant is working shift hours, allowing him to be so generous with his time.

Andrew has a family member and a close family friend with MS, so understands the challenges MS can bring. Making a difference in life is important to Andrew. Brightening somebody's day and making people smile, when they might be having a rough time, is something Andrew does so naturally.

Volunteering in the Coe household is a family affair! Andrew's Mother, Beryl has volunteered for MS Auckland for many years and continues to help out with our Street Appeal. During the school holidays Andrew's daughters Gabrielle (17 years old) and Therese (14 years old) will also lend a helping hand in the office, which gives them in return an awareness of the bigger world and a sense of virtue, which is important for the Coe family.

Andrew's philosophy is to always be thankful for your health and believes strongly in giving back and opening your eyes to the world.



Gabrielle and Therese



Andrew last year in Europe

Graham and Judy Wear remember Steven.

Steven was in his mid 20's, living in England and working as a jazz musician, when he got Multiple Sclerosis. Graham recalls getting the phone call from Steven out of the blue saying he's been diagnosed with MS and he's coming home.

Judy was a nurse, but had no experience with MS and neither of them knew anything about it. So before Steven arrived home they were in touch with the MS Society of the North Shore and spoke to a field worker. "The field workers were tremendously helpful" says Graham. "They came to our home, and told us everything about MS and what to expect. They also informed us about the wide range of support that the society could offer".

Steven arrived home and moved back into his old bedroom. His disease progressed quickly and soon he needed a wheelchair. They were always in close touch with the MS Society. Steven met other people living with MS and became involved with a men's group that was operating at the time. They all became quite close and enjoyed getting together.

Eventually Steven was confined to his bed. He contracted pneumonia, and sadly was too weak to fight it. Just 8 years after he was diagnosed, Steven passed away in his family home.

Graham and Judy were always grateful for all the support and assistance the family received from the MS North Shore Society. In fact they were so appreciative that they became involved with the Society. Graham became the president, and Judy, who was a committee member, helped out with all the activities and events.

Judy in fact gave so much of her time that she was made an honorary member of the Society for all the work she did over the years. Graham went on to become the vice-president of MS Auckland when Auckland and the North Shore amalgamated. He now continues to serve on the MS Auckland Committee and is a member of the MS Auckland Region Trust Board.



Pat Hunt (friend), Judy and Graham



*Steven's brother, Billy, Steven's girlfriend, Julie, and Steven.
The photo was taken soon after Steven
was diagnosed with MS.*

When doing their wills both Graham and Judy felt it only right to remember their youngest son, Steven. Their older two children, Jackie and Billy will receive a share of their estate, with a portion going to MS Auckland in memory of Steven. They feel that the society did so much for Steven and their family that this is only appropriate.

MS Auckland would like to thank the Wear family for including MS Auckland in their will. Without the generosity of everyday Kiwis, the services MS Auckland provides wouldn't exist. Your support 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 MS 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.

research day – 1 April 2017.



Event details:

- Date:** 1 April 2017
- Time:** 9:45am for a 10:15 am start. The event will close at 2:45pm.
- Venue:** Alexandra Park Racecourse, Greenlane, Auckland
- Catering:** Coffee and tea and muffins will be available at 9:45
A buffet lunch is included in the day
- Cost:** The day is free to all people of the MS Auckland community.
Friends, family and members of other societies may attend with a donation at the door
- Registration:** Numbers are limited and registration is essential. Please register by e-mailing events@msakl.org.nz or calling our office 09 845 5921

Programme

The programme this year will have 3 key note speakers. To see the schedule of the day please refer to our website – www.msakl.org.nz.



Dr Ernie Willoughby

Is a senior neurologist in Auckland with a specialty in Multiple Sclerosis, as well as a senior lecturer in the Department of Medicine at the University of Auckland. Dr Willoughby has been a strong supporter of MS Auckland and has spoken at our Research Days in the past. He is always a firm favourite.

We asked Dr Willoughby what he feels would be most relevant to discuss for Research Day this year and he stated that 'the most relevant topic might be an update on drug treatment, especially with the new Pharmac guidelines which have made a big difference'. We look forward to having Dr Willoughby with us again and getting the latest update.



Gilly Davy

BSc Hons Physiotherapy; PG cert Health and Rehab Science; Honorary Clinical Fellow of Australian Catholic University; Senior Neurological Physiotherapist and Clinical Director of Connect Neuro Physiotherapy

We are delighted to have Gilly joining us this year. Gilly is an expert neurological physiotherapist and clinical director of Connect Neuro Physiotherapy in New Zealand and graduated from the University of Brighton in the UK in 2004. She is currently a Clinical Fellow of Australian Catholic University and was awarded Australian Physiotherapy Association IPSEN 2015 Award for Special Commendation for Achievement in Neurological Physiotherapy. Gilly is extremely passionate about neurological rehabilitation and was one of the first private neurological physiotherapists globally to provide successful tele-rehabilitation services for neurological conditions. She is the founder of MS Get a Head Start and driven to help those with MS optimize their ability to manage their MS.

Gilly will discuss :

MS and Exercise – How to take the Power back

The treatment of MS has changed, with building research and evidence proving that exercise can have neurological protective effects and can significantly improve quality of life and symptoms. There is an urgent need to increase exercise and physical activity levels of those living with MS.

Gilly will discuss the latest evidence based approaches to the core principles of exercise for MS, breaking down the barriers to exercise and teaching you how you can incorporate the principles into your current day to day life.

Dr. Terry Wahls

We are thrilled to have Dr. Terry Wahls presenting to us for the very first time in New Zealand. Her presentation will be remote from her home in Iowa, USA.

Dr Terry Wahls is a clinical professor of medicine at the University of Iowa where she teaches internal medicine residents, sees patients in a traumatic brain injury clinic, and conducts clinical trials.



She is also a patient with secondary progressive multiple sclerosis, which confined her to a tilt-recline wheelchair for four years. But thanks to the power of The Wahls Protocol, which is based on functional medicine and the Wahls Paleo™ diet, Dr. Wahls restored her health and now pedals her bike five miles to work each day. She is the author of *The Wahls Protocol: How I Beat Progressive MS Using Paleo Principles and Functional Medicine*, *Minding My Mitochondria: How I Overcame Secondary Progressive Multiple Sclerosis and Got Out of My Wheelchair* and teaches the public and medical community about the healing power of intensive nutrition.

Dr Terry Wahls will discuss:

Diet and Neurodegeneration and NeuroRestoration: Using Food Choices to Stabilize and Reverse Neurodegenerative Disease Processes

In this session, Dr Wahls will explore the environmental factors that influence the speed of aging and neurodegeneration of the brain. She uses diet and lifestyle interventions based upon Functional Medicine and Ancestral Health principles to treat a wide variety of neurological, medical and psychiatric disorders.

In addition, she conducts clinical trials using diet and lifestyle to treat multiple sclerosis. She will review the rationale for the specific food groups that are important for neuro repair and the food groups that promote neurodegeneration. In addition, Dr Wahls has a personal connection to these interventions, having experienced 7 years of steady decline due to progressive multiple sclerosis, and even spent four years dependent upon a tilt recline wheelchair. Thanks to the power of functional medicine, diet and lifestyle interventions she restored her health and vitality, and now bikes to work. She will review her personal story, the scientific rationale for dietary and lifestyle interventions which she used for her recovery, in her clinical practice and in her clinical research.

MS Auckland AGM.

You are cordially invited to attend the Annual General Meeting of MS Auckland.

Date: Wednesday 12 April 2017
Time: 5:30pm – for wine and nibbles
6:00pm – AGM, followed by our very special guest speakers
Venue: ILS, 14 Eron Avenue, Royal Oak, Auckland

Special Guest Speakers

Dr Ernie Willoughby and Dr Wallace Brownlee

If you would like to nominate yourself or someone else to be on the MS Auckland Committee please contact MS Auckland or visit our website – www.msakl.org.nz – for nomination and proxy forms.

a journey to Singapore for hematopoietic stem cell transplantation. (HSCT)

On the 20th of March Christine will board a plane to Singapore where she will stay for three months to undergo HSCT. Her partner, Simon will accompany her and she has the blessing of her children. The procedure will set her back \$120,000 (Singapore dollars), plus the cost of airfares and accommodation. She will arrive one month before treatment, then be hospitalized for 3 to 4 weeks, and then remain in Singapore for a month after treatment to make sure all is going well.

The decision to undergo HSCT treatment cannot be done lightly. It is still an experimental treatment and while it may be considered a plausible treatment for some MS patients, the trials are still on-going and therefore it lacks formal approval from health officials.

However HSCT treatments are available in clinics around the world, including Mexico, Israel, India and Russia. Costs of the procedure vary greatly, with Singapore being at the higher end.

Christine will celebrate her 54th birthday this year. She has been living with MS for 20 years. She gets around with the help of a cane, and is very fit and active. Twice a week you will find Christine at the gym, and once a week doing Pilates.

Throughout her life Christine has been a fighter and an achiever. She was an international horse competitor in endurance riding, racing up to 160 kilometers a day! She never let her MS stop her and continued to win many international competitions. However about 5 years ago her MS really took hold. That was when she was told her relapsing-remitting MS had now become progressive.

Originally from the UK, she spent her time living between the UK and New Zealand. Once the MS became progressive though she sold her horses and came to live in New Zealand. Her MS continued to get worse. There was nothing anyone could do for her. Her exercise regime and her attempts at some diet changes did make her feel healthier, but it wasn't a cure and it didn't halt the progression of her MS.

About 6 months ago she started investigating HSCT treatments. She found an HSCT group on facebook and joined it. The group consists of people who are considering treatment and those who have undergone it. Christine says that all the feedback on the treatment is brilliant. There has been no negative feedback.

Everyone is different of course and some people just find their walking and fatigue improving or greater tolerance to heat. "Little things mean a lot when you have MS" she says. "I will be happy if the treatment halts the progression – that's all I'm hoping for - although more would of course be great!"

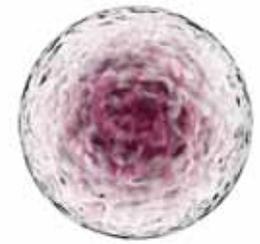
We will be keeping in touch with Christine over the coming months. Our thoughts and good wishes are with you Christine, for a safe journey, a speedy recovery and a wonderful result.



Christine on her horse at the start of a competition with her crew member, Lisa.

***Have you undergone stem cell treatment?
We would love to hear about your
experiences at info@msakl.org.nz***

stem cells hold promise for MS.

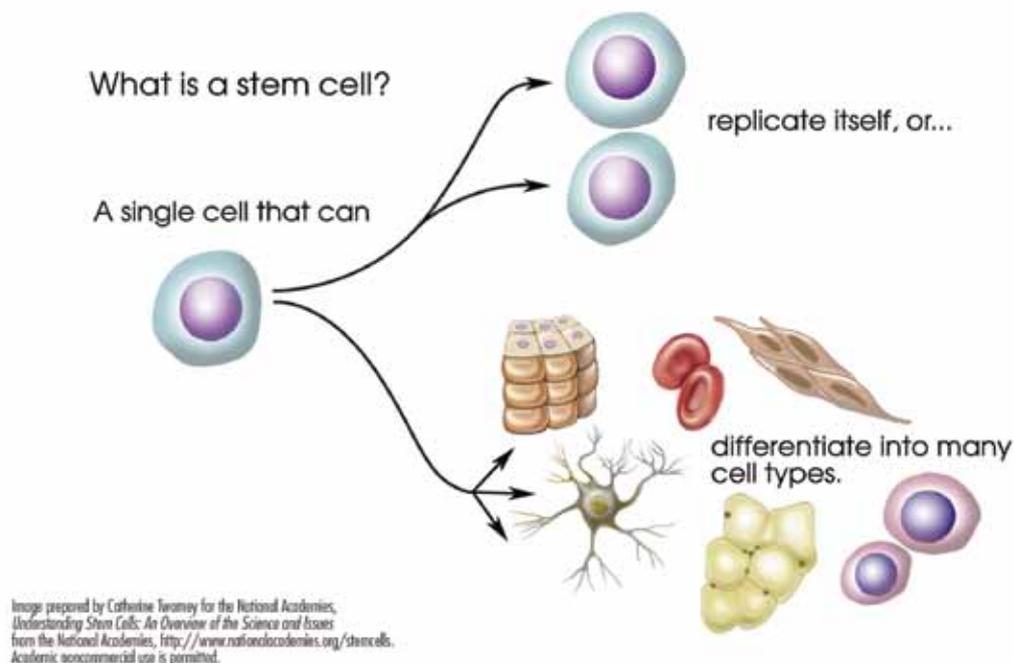


The following has been taken from the National MS Society in the USA
www.nationalmssociety.org/Research/Research-News-Progress/Stem-Cells-in-MS

There is exciting and innovative research and progress occurring related to the potential of many types of stem cells for slowing MS disease activity and for repairing damage to the nervous system. In light of the urgent need for more effective treatments for MS, particularly for those with more progressive forms of the disease, we believe that the potential of all types of cell therapies must be explored.

Stem cell therapy is any treatment that uses or targets stem cells, which are the types of cells that differentiate into many different specialized cells in our bodies. Stem cells are found in both embryos and adults.

Many types of stem cells are being explored for their potential benefits for treating multiple sclerosis. Only when the results of these and subsequent clinical trials are available will it be possible to determine what the optimal cells, delivery methods, safety and actual effectiveness of these current experimental therapies might be for people with MS.



Different Types of Stem Cells

- **HSCs (haematopoietic stem cells)** – adult stem cells that are found in bone marrow and blood. HSCs are capable of producing all of the cells that make up the blood and the immune system
- **MSCs (mesenchymal stem cells)** – adult stem cells found in several places in the body, including the bone marrow, skin and fat tissue. They produce cells which help other stem cells function properly
- **NSCs (neural stem cells)** – specialized stem cells responsible for repairing nerve-insulating myelin in the brain. These can be derived from other types of stem cells such as mesenchymal cells
- **hESCs (human embryonic stem cells)** – stem cells derived from donated embryos. They can naturally produce every type of cell in the body. One concern about their potential therapeutic use is that they have been found to cause tumors
- **iPSCs (induced pluripotent stem cells)** - are engineered from adult cells to produce many types of cells. One concern about their potential therapeutic use is that they have been found to cause tumors

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 (1 Forrest Hill Road, Milford) | Diane Hampton 021 859 187 | First Saturday / Month 12.30pm |

Consumer Information 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. GIL 0916-162 TAPS MR4974 essence Reference: 1. Gilenya Consumer Medicine Information available at www.medsafe.govt.nz
Model is for illustrative purposes only

Only think about your MS once daily

Relapsing multiple sclerosis may be there every morning, but that doesn't mean it has to always be on your mind.

With a treatment routine as simple as one pill a day, Gilenya can let you focus on the life you want.

**Ask your doctor
about Gilenya.**

**GILENYA**
(fingolimod)

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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

MS Auckland is a charitable organisation. Joining our community is by donation. A tax receipt will be issued for all donations either on receipt (annual donation), or at the end of the financial year (for regular giving). Monthly donations of \$30 or an annual donation of \$360 or more also entitles you to free participation to our Wellness Workshops and our annual Christmas Lunch.

Date: ____ / ____ / ____

Please select one of the following:

I have MS A family member has MS I am a health professional Other _____

First Name: _____

Date of birth: ____ / ____ / ____

Surname: _____

Email: _____

Address: _____

Home ph: _____

Work ph: _____

_____ Post code _____

Mobile: _____

I would like to make an annual donation of

\$30

\$50

\$100

\$360

Other _____

I would like to give a regular amount of

\$10

\$20

\$30

\$40

Other _____

Frequency

per week per fortnight per month

Payment Options: I would like to pay by: Automatic debit (see account details below) Credit card

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

Card No.

For regular giving via credit card we will contact you to confirm details.

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)

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
PO Box 33574, Takapuna, Auckland 0740
P: 09 845 5921 | Email: info@msakl.org.nz



For more information visit
www.msakl.org.nz

Get started with **TECFIDERA**[®] (dimethyl fumarate)^{1,2}

An oral treatment for relapsing multiple sclerosis¹



Talk to your neurologist to see if TECFIDERA is suitable for you

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, leucopaenial, 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 – Proposals regarding multiple sclerosis treatments (16 October 2015). Available at: <https://www.pharmac.govt.nz/news/consultation-2015-10-16-ms-treatments> Accessed February 2017.

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