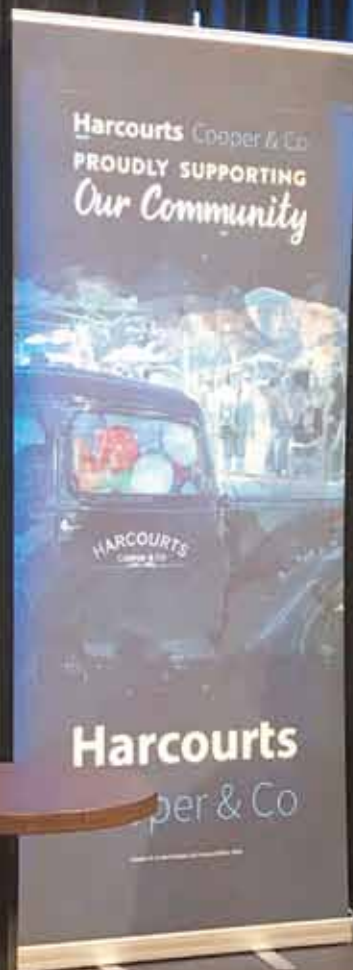
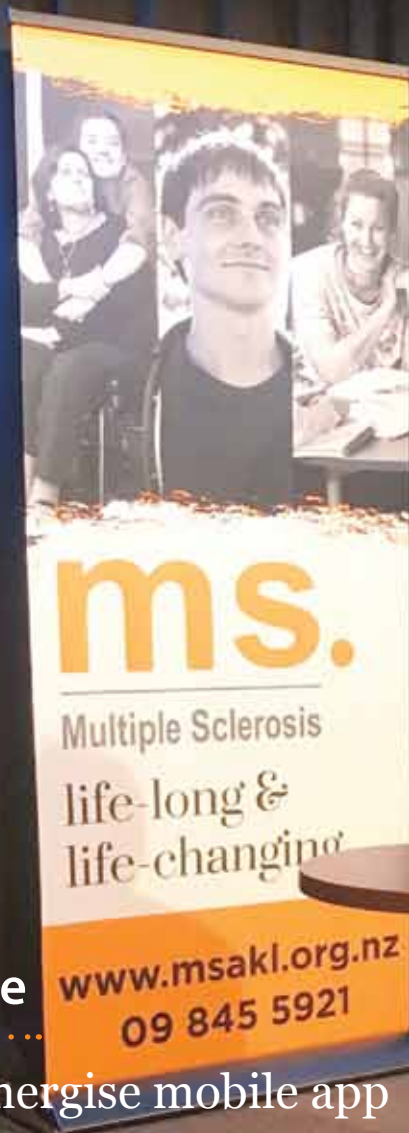


Sam Smith at our comedy night

*Laughter may not be the best medicine,
but it is the most fun to take!*



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www.msakl.org.nz
09 845 5921

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ms.
Multiple Sclerosis
AUCKLAND



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.

SANOFI GENZYME 

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our people.

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Diane Hampton (North)
Andrea Kortas (West)

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and Print Monkey
www.printmonkey.co.nz
for the printing.*



*Thank you to Pub Charity
Limited for funding Multiple
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a few words from Ingrid.

Our General Manager

Adios winter! Hello Spring! Spring officially begins in my books with the Spring Equinox on Saturday the 23rd of September - coincidentally, the same day as the NZ election. I have a feeling that there will be a fair bit of change in the air, with both the political climate and the amount of sunshine hours. Time will tell!

As I write this I am thinking about my upcoming brief trip to Vancouver to visit with my mother. My mother is 83 and is physically very weak and reliant on her wheelchair – hence access issues are at the top of my mind. I'm hoping to take my mother to some of her favourite places, like the Art Gallery, the beaches, the theatre and cafes – yet I have to think if I can get her to all these places. I have no idea how accessible Vancouver is as I've never had to think about accessibility issues before. Wouldn't it be great if all places were accessible always? I've gotten involved in the Access Matters campaign and I hope you have a look at it and decide to add your name to the campaign as well. Let's make Auckland a fully accessible city! Find out more on page 17.

There is always a lot to do when I get back from some time away from the office. I came across this 'real' To Do List to help keep me grounded:



I hope you enjoy this edition of the magazine as much as I enjoyed pulling it together. I'm always fortunate to have great contributors and wonderful people to meet and interview. Huge thanks always to Susan from Underdog Design, who designs and sets the magazine out so we can send it to you in this lovely format. We are so lucky to have found her!

Happy spring! With warm wishes,
Ingrid

our new MS ambassador – Lady Henry!

MS Auckland is thrilled to have Raewyn Henry join us as an MS ambassador, joining long time ambassadors John and Lorraine Street.

Raewyn has never been one for the spotlight, happy for her husband, former All Black coach, Sir Graham to take the spotlight. However earlier this year we saw Raewyn in the spotlight, when she put on her Centre Bib and played in the World Masters Netball team. Netball is clearly still one of Raewyn's passions, however she is also actively involved in helping out a number of charities.

Raewyn has friends with MS and knows all too well how unpredictable and challenging it can be to live with the condition.



As our MS ambassador she will be helping to increase public awareness of MS and raise funds to support people living with MS. Thank you, Raewyn!

MS Auckland office is located at
5 The Strand, Takapuna

Office Hours

Monday – Friday 9am to 5pm

Phone number: 09 845 5921

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info@msakl.org.nz

Kirsty@msakl.org.nz

Becky@msakl.org.nz

events for your calendar.

September
/October

Upcoming events



Saturday
30th September

Wellness Workshop
10am to noon
*'Taking Charge of
Cognitive Changes'*

Saturday 11th November

Newly Diagnosed Day

These half day events are very beneficial for people who have been newly diagnosed. Attendance is generally by invitation, however if you have not been to one, or feel you could benefit from a refresher please talk to your Field Worker or the MS Nurse about attending, or call the office.

Sunday
10th December

Christmas Lunch

Mark this date in your calendar! More information will be coming out shortly.

Breaking News! - Bike the Bridge, which usually takes place in November will now be on Sunday the 18th of February 2018! This gives you lots of time to take your bike out over the summer months and prepare for this fun, family event.

The best way to keep in touch regularly with upcoming special events is through our e-newsletter and website. If you do not receive the monthly e-newsletter you can sign up on our website – www.msakl.org.nz or contact Becky at the office on 09 845 5921.

taking charge of cognitive changes.

Taking Charge of Cognitive Changes in MS

30th September 2017 | 10:00 am - 12:00 pm
Remuera Club| 27-33 Ohinerau Street
Remuera, Auckland 1050

About the Facilitator:

Dr John Davison is a senior clinical psychologist with experience in both clinical and academic positions in New Zealand, Australia and Singapore.



This workshop will aim to help you understand the brain changes that can occur in MS, recognise cognitive changes specific to MS, and more importantly, take charge of these changes rather than be controlled by MS.

More about the Workshop:

People with MS often experience mild to moderate changes in their thinking abilities and feel that their thinking is 'not what it used to be'. Changes in cognitive functioning can be an effect of brain changes (which are different for everyone) and can be exacerbated by other symptoms of MS, such as fatigue and sleep problems. Cognitive changes can be frustrating, make us feel less confident in ourselves, and sometimes lead to us withdrawing from daily activities or social situations. However, more often than not, people with MS are able to develop effective ways for managing these cognitive changes, adapt to their circumstances, and live productive, fulfilling lives. Learning skills early on to compensate for cognitive changes can be especially important to maintaining cognitive abilities as MS progresses.

from the field.

In this article, Dianne sets out to remind everyone who your Field Workers are and what they can do for you.



I'm **Dianne Bartlett**. We have two Dianne's working as Field Workers for the MS Society and this can cause a little confusion at times. So to differentiate, my name is spelt with two 'n's'. If you wish to email me, please make sure you put the two n's in your email otherwise your email will go to 'the other one' I have worked for MS Auckland now for 9 years.

My email address is **dianne@msakl.org.nz** My cell phone is **021 845 903** or you can reach me on **09 845 5921** extension **220**. I look after the South Auckland and East Auckland areas, which is quite a large geographical area, from Mangere Bridge in the West, the Eastern Beach area in the east down as far as Kaiawa on the east coast. Tuakau is the southern most area and up on the Waiuku peninsular and any area in between. This is largely the Manukau DHB region.



The 'other one' is **Diane Hampton** spelt with one 'n' Diane has worked for the MS Auckland for some 13 years now. Diane's email is (and remember only one 'n') **diane@msakl.org.nz** Diane's cell phone is **021 859 187** or you can reach her on **09 845 5921** extension **219**. Diane covers the North Shore from Devonport, Bayswater, Belmont, Takapuna, Milford, Castor Bay to Long Bay. Northote, Birkenhead, Birkdale, Beachhaven to Glenfield through to Greenhithe, Paremoremo, Albany, Albany Heights.



Carol Andrews has been with us now for four years and some of you will know her through the Minimise Fatigue, Maximise Life (MFML) course that she facilitates. Carol's email address is **carol@msakl.org.nz**. Carol's cell phone is **021 959 187** or she can be reached on **09 845 5921** extension **222**. Carol covers central Auckland and surrounding areas such as Ellerslie, Mt Wellington, Panmure, St Heliers, Mission Bay, The Orakei Basin, Pt Chevalier, Mt Albert, Avondale and Blockhouse Bay. She also covers Waiheke Island - actually the Auckland DHB area.



Last but by no means least, is **Andrea Kortas**. Andrea joined us just over a year ago now. Andrea's email is **andrea@msakl.org.nz**. Andrea's cell phone number is **021 959 189** or she can be reached **09 845 5921** extension **221**. Andrea's area covers West Auckland and Rodney within the Waitemata DHB including Green Bay and Titirangi and surrounding areas, West Coast beaches up to Kumeu and Riverhead, Whenuapai, Herald Island, Hobsonville, Kaukapakapa, the Whangaparaoa Peninsula up to Wellsford and everything in between. Another large geographical area!

What do we do -

We are here to support you. Google tells us that support is "the perception and actuality that one is cared for, has assistance available from other people, and that one is part of a supportive social network". And that is exactly what we do.

If we break that down further, here are some of the ways in which we can support you:

1. We visit your home so that we can talk together in a non- threatening environment. We are generally not governed by a clock so that we can talk openly about all sorts of things MS no matter how silly you may think they are. Over the years we build a good strong relationship with each other so hopefully you will feel comfortable contacting us if the going gets a little tough.
2. We extend our support those you are indirectly impacted by MS – such as your family and friends.

3. We can connect you with other people who have MS, so that you have someone who knows and understands just what you are going through.
4. We provide you with books, brochures, pamphlets and other written information all free for you to keep as future reference.
5. We can refer you to such places as Physiotherapists, Occupational therapists, Needs Assessments to assist you getting some personal care help and house work done, Lottery Grant applications, just to name a few, to make sure you get the services you need to help you lead an active and independent life.
6. We advocate for you. This is a biggie. We are often asked to go to work places to explain MS and how employers can help make work life a little easier on an employee living with MS. We are also available to accompany you when you visit other places such as WINZ, Housing New Zealand, and other places of 'officialdom' and where ever you may feel you need some support.
7. We listen. Sometimes it's good to dump, to share the load and hopefully we can help lead you in the direction you feel you need to go. Or not. Just listen!
8. We work closely with the MS nurses and often collaborate with them on projects and run workshops with them. They look after the clinical side of MS and we look after the community.
9. We run wellness workshops that you are all invited to. We advertise these in this magazine and also talk about them in the support groups.
10. We run Newly Diagnosed Days, providing time and space for people to gather more information and a better understanding on a new diagnosis of MS.
11. We run Support groups and Water therapy groups (dates, venues and times are all in this magazine for you).
12. We publish and send out our quarterly magazine to you all and to other interested people in the community. This is free to everyone. This hopefully will keep you in touch with things MS.
13. We try to raise the awareness and understanding of MS by talking to community groups and whoever wants to listen!

So now you know who we are, what areas we cover, how to contact us and how we go about doing things. Do feel free to contact us any time no matter how big or small your questions may be. If we are visiting someone and are unable to answer your call straight away, then do leave us a message and we will get back to you as soon as we can.

We all feel that it is a privilege to be invited into your homes and lives and thank you for being part of our lives.

Cheers from Dianne with 2 'n's' - Field Worker – South Auckland

from the MS nurses.

The MS Nurses, Fiona and Nazila, each work part-time. Together they cover Monday to Friday from 9am to 4pm. During holidays they have reduced availability. This will be reflected in their phone messages and automatic e-mail responses.

Multiple Sclerosis Nurse Specialists
Auckland City Hospital
e-mail – MSNurse@adhb.govt.nz
Phone – 09 307 4949 ext. 25885#



volunteer profile.

Beverley Kempthorne - Beachlands Street Appeal Coordinator

They say if you want something done ask a busy person. Beverley is certainly a busy person! She was always a very active and outgoing person prior to developing MS. While her MS has slowed her down a bit physically, it certainly hasn't slowed down her enthusiasm for life and her desire to look after herself and give back to her community.

Three times a week you will find Beverley in a gym working out, once a week doing a hydrotherapy class at Lloyd Elsmore Pool and one day a week on her favourite horse with Riding for the Disabled.

Beverley has also been the Street Appeal area coordinator for the Beachlands area now for the past three years. She gets other volunteers from her local MS support group to help her out and also manages to get a free advertisement in the Pohutakawa Coast times calling for more volunteers over the two days.



You can find Beverley and her volunteers during Street Appeal outside the Beachlands Postshop, or by the Countdown, or they may also be at sites in Maraetai or Whitford.

The annual Street Appeal is an important event on the MS Auckland calendar, raising much needed funds to keep the society running. All people collecting over the two days are volunteers with hundreds needed to get the reach throughout all communities. We are so thankful for Beverley, and others like her, who lead a local area. It takes so much pressure off the office staff to be filling all the sites!

Thank you, Beverley! You are a star!

Sofia Radak – running for MS.

On Sunday the 29 of October Sofia will be getting up probably before the crack of dawn to get to the starting line of the Auckland Half Marathon. While she is quite an active person, this will be her first time running a half marathon. Her motivation is her father, who lives with MS. Sofia saw this as an opportunity for her to help out the MS society that supports her father and others in Auckland living with MS.

Sofia is training every day, with the occasional rest day. She feels the hardest part is in preparing her body, both physically and mentally, for the 21 kilometer run. Sofia has set up a give-a-little page so that people can support her efforts by donating to MS Auckland. She is very grateful to all those who have already donated, and hopes over the coming weeks to raise more funds.



To support Sofia to raise funds for MS Auckland please go to <https://givealittle.co.nz/fundraiser/running4ms>

hydrotherapy.

There are so many studies now that show how exercise can improve a host of MS symptoms – including walking speed, balance, brain fog, fatigue and depression. It's important to find an exercise that you enjoy. That way it is more likely that you will stick with it. It's also important to choose something that matches your level of ability.

If you haven't tried Hydrotherapy yet then we highly recommend that you give it a go. You get your first 2 classes free to see if it is something that you enjoy and want to continue. After that the cost is only \$50 for 10 classes.

Hydrotherapy isn't just a good workout that can be adapted to almost all levels of ability; it's a lovely social activity. Many of the swim groups will meet afterwards for a coffee and a chat. One group even gets together for the occasional evening outing with their partners. And what's more, they are all very friendly and welcoming to new people to join them.

Water exercises are considered to be one of the most adaptable and effective ways to get moving. In a 2014



study published in the European Journal of Experimental Biology, researchers offered 30 men with MS 8 weeks of one hour aquatic exercises. Another 30 men with MS were in the control group and received no intervention. The result showed overwhelmingly that the group with the weekly water exercise had improved balance.

To find out more about Hydrotherapy Classes please contact your MS Field Worker or the MS office (on 09 845 5921). The classes are available for people with other neurological conditions as well on the recommendation of one of the Physiotherapists at Rope Neuro Rehabilitation, who conduct the classes. Rope can be contacted on 09 623 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

Christine returns from Singapore.

Short hair and big smiles!



In March this year I talked to Christine just before she left for Singapore about her upcoming trip to Singapore for HSCT treatment. This was written up in our March magazine.

Christine is now back! I met up with her in a café in Parnell. She looked fabulous! Here are some of the things we talked about:

Me: What was the whole experience in Singapore like for you?

Christine: In total I was 2 and a half months in Singapore. Of that I only had 2 weeks in hospital. It wasn't pleasant, but it certainly wasn't as bad as I had expected. I only had one really bad day with the chemotherapy. I needed to have 3 blood transfusions, which was unexpected, and because I have 0 negative blood which is not that common, they had to run around to find the blood I needed!

They put tubes in your neck which you have in for about 2 weeks. It's awkward and makes it a bit hard to sleep. When they come out they put a tube in your chest.

It was great to have my partner there and both my sons came over to see me for some of the time. One lives in the UK and the other in New Zealand.

Me: Did you spend much time preparing yourself for this?

Christine: Well I did get my affairs in order. The treatment is still experimental and while the risk is small it is still there.

I worked hard at getting myself in peak physical condition. I think your chances of a smooth recovery is better if you're in good shape going in.

Me: You said that all you wanted from the treatment was for the progression to halt. Do you think this has been achieved?

Christine: It's hard to know because the treatment hasn't been around long enough. Even if it halts things for 5 to 10 years it will be great. I will have an MRI every 6 months. While the old lesions will still be

Ingrid talks to Christine 2 months after returning from Singapore



Christine in Rotorua

there, the hope is that no new ones appear. I am feeling great though. I had been walking with a walking stick for about 6 months prior to the procedure, but don't use one at all now. I have so much more confidence. People are noticing a big difference in me too. I go to the gym regularly and do pilates and both trainers say there is a big difference in my abilities. I still have to be careful though. If I overdo things I start noticing a tingling in my legs. Then I have to stop and rest. I also avoid crowded places as much as possible. I have been well since coming back but I don't want to take any risks as my immune system is probably still weak.

I have so much more confidence now. I had some friends visiting from overseas and we went to Rotorua together. I actually went on a native forest zipline tour with them. It's something I never would have had the confidence to do before. I let the guide know that I might be a bit slow, but in the end I felt good because I kept up with the group and I wasn't even the slowest!

Me: Any regrets?

Christine: None at all. Going to Singapore suited me. There was only a 3 months waiting list which was good. I didn't want to wait any longer as I felt I was going downhill rapidly.

Me: What are your plans now?

Christine: My plan is to live!

food & recipe.

Our recipe this quarter has been kindly provided by our volunteer, Wendy Wood. Wendy has MS and is a strong follower of Overcoming MS (<https://overcomingms.org/>) which promotes the integration of diet and lifestyle changes into standard medical management of MS. The OMS programme was developed and rigorously researched by Professor George Jelinek who was diagnosed with MS in 1999.



This recipe came from the Mana retreat that Wendy attended in 2012.

Red Dragon Pie

Serves 4-6

First catch your dragon!

Ingredients

1 1/4 cups brown or green lentils (or 2 x 400gm cans, drained)
Bay leaf
2 onions, chopped
4 cloves of garlic, chopped
Big thumb of ginger, chopped
2 sticks of celery, chopped
2 carrots, chopped
Can of tomatoes
1/4 cup tomato puree.
3 tablespoons soy sauce or tamari
Generous handful of herbs, chopped - parsley, chives, marjoram, rosemary etc
1kg root vegetables, peeled and chopped - potato, kumera, pumpkin etc
'Milk' - soy, rice etc
Extra virgin olive oil
Salt and pepper to taste



Instructions

Cover lentils and bay leaf in water and cook until tender - 30 - 40 minutes. I use a pan that can also go in the oven.

Steam onions, garlic, carrot, celery and ginger until soft.

Add to lentils with tomatoes, tomato puree, soy sauce or tamari and plenty of chopped fresh herbs, and cook until soupy.

Cook a selection of root vegetables (potato, carrot, parsnip, pumpkin, yams) until soft and mash with soy or rice milk and a splash of extra virgin olive oil.

Tip: I cook them in the water left over from steaming the onions etc, then drain the final vegetable cooking water into the lentil mix.

Check seasoning of lentil mixture and mashed vegetables.

Top lentils with mashed vegetables and bake at 180 deg C for 45-50 minutes until golden.

Tip: I keep a bag of chopped onions, garlic, and celery in the freezer ready to add to things like this. Food processor saves effort too.

street appeal.

Our Annual Street Appeal over for another year. This event sees hundreds of volunteers take to the streets collecting funds and raising awareness of MS. We are so very, very grateful to you all!! We could not do this without you. Your support helps us support people in the Auckland region who develop MS – a life-long and life changing condition for which we still have no known cause or cure.

A big thank you to the BNZ! Staff members took the day off from banking as part of their 'closed for good' community support and delivered resource boxes to collector's homes throughout Auckland.

Unfortunately we were not given permission this year to collect from a number of our top sites. Many stores now have rules around collections, such as only allowing one a month, or only one or two of their nominated charities to collect, or even not allowing any more collection outside their store at all. This will likely have an impact on the funds we can raise. Hopefully the impact isn't too hard!

If you didn't see a collector over Appeal weekend and would like to donate please go to <http://www.msakl.org.nz/donate>, or phone the office on 09 845 5921.

Thank you!



Mt Roskill



Newmarket



Countdown Pukekohe



Greenlane



Navy collectors in Devonport



St Peter's Boys



Takinini

laughter is the best medicine.

comedy night sponsored by Harcourts Cooper & Co

There is nothing better than a good giggle, or better yet a big belly laugh. Is it the best medicine? Probably not, but research shows that laughing triggers the release of endorphins, our body's feel good chemical and natural pain killer. But that's not all – laughter is credited with lowering blood pressure, reducing stress hormones, working your abs and improving your cardiac health, and boosting your immune system!

'Laughter is the Best Medicine' event was held at The Comedy Classic on Queen Street on the 29th of August to launch MS Awareness Week. The event was sold out within a couple of weeks with 120 people enjoying a fabulous night out, thanks to the 6 top comedians who donated their time on the time and gave us all a great show and tears of laughter.

A great big thank you to:

Brendon Green, Tarun Mohanbhai, Louise Beuvink, Guy Williams, Dai Henwood and our very own Sam Smith, who was also the Master of Ceremonies on the night.

Macpac who have been good supporters of MS, primarily through the 'Mastering Mountains' scholarship, donated 6 drink bottles which were passed on to the comedians help show our deep appreciation for their generous support.

MS Auckland Treasurer Peter Wood and his wife and Committee member Maureen, donated the top raffle prize of a week long stay in a luxury apartment on Lake Taupo. This prize along with the 2nd prize of 4 cinema tickets and 3rd prize tickets for 4 people to attend the filming of Jono and Ben, made for a great raffle on the night.

A big thank you also to our community sponsor Harcourts Cooper & Co – they have been so wonderful with their support of us over the years. And thank you too to The Comedy Classic Club for hosting us. We hope to make this event an annual one in our calendar!

'A day without laughter is a day wasted'

– Charlie Chaplin



Guy Williams, Brendon Green and Sam Smith



Raewyn Henry doing the prize draw with Sam and Kirsty



Kirsty from the MS office thrilled to meet Guy Williams

to complain or not to complain...

Kiwis tend to be quite complacent people and not ones to generally complain. Sometimes though, especially when it comes to your health, or the health of others it is important to let service providers know that they need to do better. In this article West Auckland/Rodney Field Worker, Andrea Kortas, looks at the process of making a complaint.

At some point in your life, you have probably all been in a situation where you were not happy with the health or disability service that you received (or a lack thereof)! We all have the right to make a complaint, but sometimes the process can seem daunting, or perhaps you don't know where to start? This article will provide some key tips to make the process easier for you and some specific information on complaining to the District Health Boards (DHBs).



Know your rights!

Before making a complaint, it's important to know your rights when receiving a health or disability service. The Health and Disability Commissioner (HDC) has a Code of Health and Disability Services Consumers' Rights. Most good health and disability services will have a copy of this available on their wall, or in a brochure. You can read and download the Code of Rights here: <http://www.hdc.org.nz/the-act--code/the-code-of-rights>

We usually have copies of this brochure available in our MS Auckland office. Please contact your Field Worker if you wish to receive a copy of the brochure. HDC also provides the brochure in many languages other than English.

If you are unsure of whether or not your rights have been breached, you may request to seek free legal advice from a lawyer at your local Citizen's Advice Bureau or you may phone Auckland Disability Law (ADL) (see details below), who provide free legal services to disabled people associated with their disability legal issues.

Where to start?

Now that you know your rights, you may wish to make a complaint. As a general rule, it is best to make a complaint in writing so that there is written evidence of the complaint being made. Ideally the complaint should be made as soon as possible after receiving the service that you wish to complain about. If you are unable to write, have someone you know and trust help you to write it.

Who do I write to?

It is best to write your complaint directly to the person or organisation that gave you the service, as a first port of call. If you do not receive a resolution that you are happy with, that would be the time to take the complaint to the next level up in the hierarchy. In some cases, the person or organisation may request to meet with you to discuss your complaint, if it cannot be resolved through written communication. If you feel uncomfortable doing this on your own, have a friend or relative support you. You can also access the support of an independent Health and Disability Advocate through the HDC, which is a free service (see details below). Climb your way up the chain of command until you reach the top level of management and if you are still not happy that your complaint has been resolved then you can seek the assistance of the Health and Disability Commissioner or Auckland Disability Law, to assist in resolving the matter.

You may also make a complaint directly to the Health and Disability Commissioner about the quality of health or disability services provided to you or someone else by completing their online complaint form here: <http://www.hdc.org.nz/complaints/making-a-complaint/online-complaint-form> or contacting them on the details below. They recommend that this is done as a last resort, after following all of the above procedures.

Tips for writing the letter:

When writing your complaint letter, you will need to outline exactly what you are complaining about, followed by the requested outcome that you hope to achieve through writing your complaint. Also include a time frame

within which you hope to receive a response and resolution. If you have any evidence of what happened, be sure to attach this to your letter. When writing, it is best to list the facts, describing what happened and to remain polite. You may describe how you felt as a result of the incident you are writing about, but I would advise against writing in an abusive or accusatory manner. No matter which level of the hierarchy you are complaining to, follow this same process. If you need help with how to format your letter, you can find some tips, templates and examples here: <http://www.wikihow.com/Write-a-Complaint-Letter-to-a-Company>

Key contact details:

The Health & Disability Commissioner

Postal Address: PO Box 1791, Auckland
Phone: (09) 373 1060
Other areas: 0800 11 22 33
E-mail: hdc@hdc.org.nz
Website: www.hdc.org.nz

Contacting an advocate:

Free Phone: 0800 555 050
Email: advocacy@advocacy.org.nz
Free Fax: 0800 2 SUPPORT / 0800 2787 7678
Or view the following link:
advocacy.hdc.org.nz/find-an-advocate

Auckland Disability Law

Postal address: PO Box 43-201, Mangere, Auckland
Physical Address: Mangere Community Law Centre, Unit 9, Shop 27, Mangere Town Centre
(wheelchair access available)
Phone: (09) 257 5140
Fax: (09) 275 4693
Mobile Number: 027 457 5140 (text only)
E-mail: info@adl.org.nz
Website: aucklanddisabilitylaw.org.nz

Complaining to the District Health Boards

Use the following procedures first, but remember if you are not happy with how your complaint was handled, you can also contact the Health and Disability Commissioner. When writing a complaint to a DHB, remember to include the patient's name, date of birth, NHI number (if you know it), and the contact details of the patient or the person writing the letter – including address, phone number and email. If relevant, also include the dates of the patient's care and location, for example, the ward name or clinic name. The DHBs love positive feedback too!

Auckland DHB

The following link provides all you need to know: <http://www.adhb.health.nz/contact-and-feedback/compliments-and-complaints>.

You can either speak to those providing your care, or the charge nurse or midwife on the ward or clinic where you are being treated. If you feel uncomfortable talking to these people, or you have a concern and aren't satisfied with their response, please contact their Consumer Liaison Team using the following details:

Email: feedback@adhb.govt.nz
Phone: (09) 375 7048

Mail to: Consumer Liaison Team, Auckland DHB, Private Bag 92024, Auckland Mail Centre, Auckland 1142

Counties Manukau DHB

The following link provides all you need to know: <http://cmdhbhome.cwp.govt.nz/for-patients-and-visitors/concerned-about-your-care/>

If you are concerned about your treatment or care (or that of a family member) you may ask any staff member for a "Happy or Unhappy with our Services" brochure, complete the form and return to the Freepost address, or you can ask to speak to the Duty Manager after hours. You can also choose to speak to a staff member or ask for a Manager (E.g. Charge Nurse, Clinical Nurse Leader or Team Leader) in the department clinic or ward.

You may also contact them using the following details:

Complaints/feedback phone: (09) 277 1667
Email: customerservice@superclinic.co.nz
Mail to: Quality Assurance Manager, Counties Manukau Health, Private Bag 93311, Otahuhu 1640, Auckland or fill out the online feedback form here: <http://cmdhbhome.cwp.govt.nz/contact-us/feedback-form/>

Waitemata DHB

The following link provides all you need to know: <http://www.waitematadhb.govt.nz/patients-visitors/tell-us-what-you-think/>
You may contact their Quality Team using the following details:

Phone: (09) 486 8920 Ext 3153
Online, using the customer feedback form here: <http://www.waitematadhb.govt.nz/contact-us/>

Mail to: Waitemata District Health Board, Quality Team, Private Bag 93-503, Takapuna, Auckland 0740

You can also enter your feedback into the complaints, suggestions and compliments box in the main foyer of the hospital you are in. Where an investigation is required they aim to complete it within 14 calendar days.

Be. employed internship.

It's a challenge all students and recent graduates know too well: how do you get your foot in the door when it seems every available position asks for experienced applicants?

Social change enterprise Be. Accessible offers a solution for eligible students through the Be. Employed Internship programme - a 4 to 16-week placement in a role that reflects the student's area of study. We are excited to offer the Be. Employed Programme to tertiary students and graduates who are looking to kick-start their career aspirations.

Be. Employed Relationship Manager Jake Mills says the programme is about providing experience and work opportunities for young people with disabilities, or access needs.

The programme is now entering its fourth year following a successful pilot in 2014. They have matched students with a wide variety of businesses including, ACC, Wellington DHB, Hamilton City Council, BNZ Auckland *"I enjoy my job because we see massive growth in people as they develop their confidence and skills in a meaningful work environment,"* says Jake. *"We received lots of great feedback from our interns and the businesses we're working with, about the value of the programme."*

The purpose of the programme is not only to create opportunities for young people with access needs, but also to establish a more diverse, open and accessible workplace culture in New Zealand.

"Access citizens are overrepresented in under-employment stats in nearly all OECD countries. In New Zealand, more than 60% of people with access needs are unemployed or underemployed."

Tessa came to MS Auckland through the Be Accessible Be Employed programme and has this to say about it: *"In 2016 I Graduated from AUT with a bachelor of international hospitality management. Finding work was not easy as I have a visual impairment which affects my working ability particularly in my field of studies."*

During my time at uni I was lucky enough to build up a great relationship with Be. Accessible and was welcomed on to their Be Employed program which helps to find those with access needs internships to gain valuable experience and confidence in the work place. I was so happy to be offered a place by the MS Auckland team working on

their big event, Clash of the Hemispheres. This experience was fantastic and the team were supportive and understanding. I have now continued working 10 hours a week with MS Auckland to help with their annual street appeal. I am extremely appreciative of Be.accessible and MS Auckland for providing this opportunity and giving me much needed experience. I am looking forward to starting working full time for an organisation in my field of study shortly and continuing on in my working career still with the team at Be. supporting and guiding me on my way."

Apply for the Internship programme now via the online application <http://www.beaccessible.org.nz/be-employed/internship-checklist2> or for more information, contact Be. Employed Relationship Manager Jake Mills on 027 699 6974 or jake@beaccessible.org.nz.

Visit www.beaccessible.org.nz to find out more about the work of Be. Accessible and the Be. Employed programme.



Be. Employed Relationship Manager Jake Mills

access matters.

The Access Matters Campaign aims to achieve new laws around accessibility so that people get to participate in all areas of life like everyone else. All too often people with multiple sclerosis are not able to access every day activities and are treated differently from others because of their disabilities.

Multiple sclerosis should not be a barrier to employment, and people's attitudes about it and all disabilities need to change. In employment, it can sometimes be difficult for people:

- During the job application process when questions are asked that force us to disclose our multiple sclerosis
- To gain the supports and accommodations (changes) needed so that we can do the job like everyone else
- To keep our jobs when things change in the workplace, for example, due to restructuring and/or our multiple sclerosis.

The Access Matters campaign is about creating law which put in place enforceable standards, for example, employment processes, job supports and accommodation plans, which promote access for all. The campaign is also about changing thinking around disability and access.



The Access Matters campaign is led by a coalition of disabled people, disability organisations and supporters. Get involved today because access matters!

To find out more and get involved go to:

<http://aucklanddisabilitylaw.org.nz/access-matters-campaign/>

<http://www.accessalliance.org.nz/>

<https://www.facebook.com/AccessForAllNZ/>



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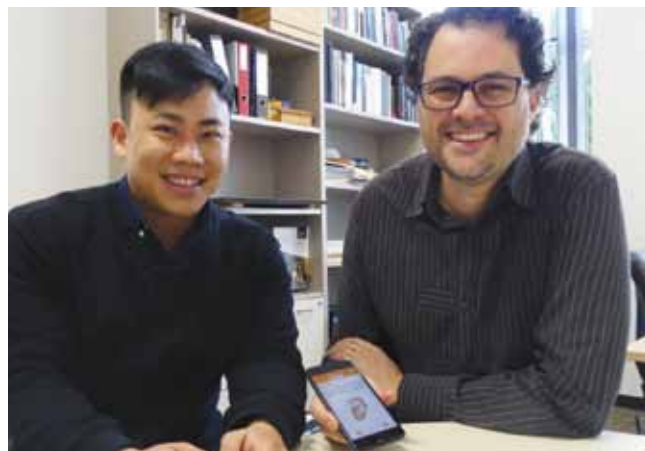
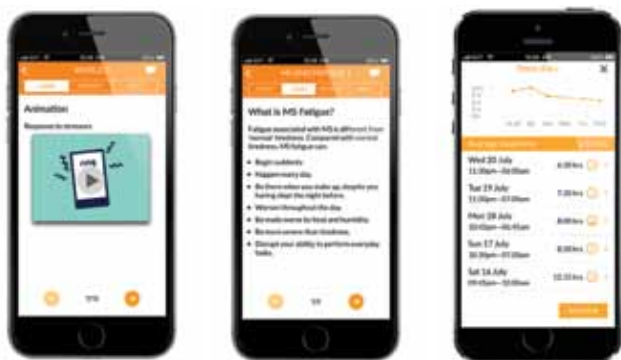
it's here! MS energise mobile app to assist people with MS fatigue!

At the end of August, after few years in the making, MS Energise was launched in New Zealand. MS Energise is a comprehensive research-supported application for people experiencing MS based fatigue. It has been developed for iPhones and iPads but the Research Team behind MS Energise is intending to launch the Android version in the near future. **Information on MS Energise can be found on their website – <https://msenergise.com>**

MS Energise is the only mobile app available which focuses specifically on fatigue, the most disabling symptom of MS, and it is based on clinical evidence. As their website states: ***Fatigue is the most disabling, invisible multiple sclerosis symptom which is experienced by majority of MS patients and it affects all spheres of their lives. MS Energise uses clinically proven approach to help MS patients to maximise their energy.***

The MS Auckland GM, Ingrid, met with two of the team – Associate Professor Duncan Babbage, from AUT University, and Wilson Huang, from AUT Ventures, a few weeks before the launch, to learn a bit more about MS Energise and what we could expect. Needless to say they both were very excited to be bringing the product to people with MS.

MS Energise uses a cognitive behaviour therapy (CBT) approach to manage fatigue. This particular CBT for fatigue management has been developed and proven to be effective by the Research Team behind MS Energise. Multiple trials showed a reduction in fatigue severity and fatigue self-efficacy four months after the CBT intervention compared to the usual care. Both the content and the mode of delivery of the MS Energise intervention are novel but underpinned by a robust evidence base.



Wilson and Duncan

Despite its efficacy, CBT is not generally available for people with MS due to prohibitive cost and scarcity of qualified clinicians. Fatigue may be discussed with an MS Nurse, Field Worker or during a review with the Neurologist, but for a symptom which affects people so profoundly, it is not given much attention.

MS Energise is divided into six areas all which impact on fatigue – Behaviour, Thoughts, Emotions, Body (physiological), World (environment) and Future. In each area you are learning, interacting and applying information to your day to day life. With hours of material, you work through it at a pace that suits you. Field tests are on-going, both in New Zealand and in the UK, with continuous updates and developments being made to MS Energise.

Even though MS Energise is designed to be a stand-alone self-management fatigue programme, MS Energise is also a great way to compliment the Minimise Fatigue, Maximise Life (MFML) course. For more information on the next MFML course in Auckland, please contact our office on 09 845 5921.

Feedback on MS Energise to date has been very positive. Being so new, there is no long-term outcome data yet on its use, but with the brilliant team behind this app I feel confident that we will see many happy users experiencing good results with MS Energise.

The MS Energise Research Team

AUT - A/Prof Duncan Babbage; Dr Kirsten van Kessel and Ann Sezier. UK - University of Brighton Prof Paula Kersten; Bournemouth University Dr Sarah Thomas and Prof Peter Thomas.

research on what people with MS require in order to receive first world care.

RESEARCH

In New Zealand there has been an increased demand for MS services - but organisations and professionals that provide the services are experiencing reducing funding. This means that about 4,000 people living in NZ with MS and their families are not being adequately supported.

The following information has been condensed from an MSNZ discussion paper that was given to various political parties.



What does first world care look like? Recent overseas research identified 4 things which MS organisations and key MS clinicians worldwide endorse:

1. Early access to disease modifying treatment (DMTs) drugs to preserve brain and spinal cord tissue
2. Early diagnosis and treatment
3. Regular monitoring and recording of the disease
4. A full range of therapies – to improve the chances of finding the best option for each person with MS

Currently New Zealand is not meeting these key recommendations. MSNZ is asking us all to reach out to our local MPs and political groups to gain their support and commitment to improve the standard of care in NZ.

What people with MS in NZ deserve is:

- Early diagnosis and treatment – This is crucial. Currently access for specialist assessments, MRIs and other diagnostic and monitoring procedures are not provided in a timely manner by many DHBs. Also people with MS often report symptoms of MS years before a diagnosis is made. Early symptoms are often misdiagnosed due to a lack of knowledge about the condition.
- Guidelines for the minimum level of treatment and support – There are no National guidelines for MS treatment which would help all people receive the same services, information and support wherever they live. Such guidelines are available in the UK and elsewhere in the world. Every New Zealander should have the right to access a neurologist within one month of referral, an MRI following their first symptom presentation and an annual review for all those diagnosed, including an annual physiotherapy review. Regular monitoring is essential and will enable personalized treatment for every person with MS.
- Access to the best frontline treatments - PHARMAC has funded some new MS treatments in recent years, but the funding criteria imposed by PHARMAC are more restrictive than overseas and not supported by current research.
- Access to specialists within a reasonable timeframe – Delays run the risk of people being unable to qualify for drug treatments by the time they are seen by a neurologist. Annual reviews must be completed on time or people risk being taken off treatment.
- Integrated multidisciplinary care – Currently DHB services are not well integrated internally. Many DHBs are not working as best as they can with services available in the community.
- More MS neurologists and specialist MS nurses – There are 34 full time equivalent Neurologists in New Zealand. By international standards there should be 74.
- Residential care in appropriate facilities – There is a lack of respite and long term residential care facilities for people with MS. This has been a long-term issue and there are no solutions in sight.
- Funded services – Funding for the charity sector is shrinking and funding for volunteer-based organisations that fulfil function that should be funded by central government is increasingly difficult to come by.

The full paper can be viewed on our website – www.msakl.org.nz

support groups.

MS Support Groups meet throughout Auckland. In Support Groups you are able to talk to other people who truly understand what you are going through and share the type of practical insights that can only come from first-hand experience. There are many benefits to joining a support group. If you haven't been to one yet, why not come along and see what it's all about? Talk to your Field Worker if you are unsure which group to go to, or if you are interested in having a support group set up in your area.

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
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
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 (1 Forrest Hill Road, Milford)	Diane Hampton 021 859 187	First Thursday / Month 10.30am
Shore Lunch Group Palmers 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, or any abnormal skin growths or changes (e.g. pearly nodules, patches, or open sores or unusual moles). 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 NZ-00109 07/2017 TAPS MR4974 essence NV8472 MSMAG 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.

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Ask your doctor
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Join the MS Auckland Community

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

ms.
Multiple Sclerosis
AUCKLAND
www.msakl.org.nz

MS Auckland is a charitable organisation. You may join our community 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. Financial membership is also available. Please contact the office for more information.

Please select one of the following:

Date: ____ / ____ / ____

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)

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The Trusts Community Foundation

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

remember us with a gift in your will.

Most gifts are made by ordinary hardworking people who would like to give lasting support to causes that are important in their lives. A gift to MS Auckland in your Will can be as much or as little as you want.

If you would like further information on 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 to mark@msakl.org.nz or Ingrid@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**

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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 – 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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