Interview with Dr Jennifer Pereira
– Neurologist with a passion for MS

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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.

*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.

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This is our last magazine for 2017. I know I say this every year, but gosh the year has flown by! They say that time flies when you are having fun!

I was very fortunate to interview some amazing people for this issue – our very own patron Dr Jennifer Pereira, who graces our cover page – Robert and Sharon (page 8) – and Megan (page 9). Meeting and getting to know such talented, kind and inspirational people in our MS community, must be the part of my work that I enjoy the most.

You will meet two of our volunteers inside these pages – Robyn (see below), and Tonia who coordinates the West Auckland Support Group. Volunteers are wonderful people. I don’t know where we would be without them! We try to profile at least one in every magazine, but really we could dedicate an entire book of all the generous people who have given their time to help MS Auckland.

Thank you for all your support through 2017. I’m excited and a wee bit nervous about 2018, as we look at ways in which we can continue to meet the growing needs of the MS community. With only 8% of our funding from the government, we rely on grants, donations and fundraising to continue to provide services. Next year we are looking to perhaps try doing things a bit differently. As I write this we are still very much still in the planning stage, so it is too early to reveal anything.

There is always a risk involved when you try something new, so it is important that we plan carefully and thoughtfully. But change is important as we seek to continue to meet the needs for all people living with MS in Auckland. Our main goal at all time is to ensure we continue to provide quality support and needed services to people affected by MS. Please keep giving us your feedback, I love hearing from you and all feedback whether it’s positive or not, is helpful.

Amongst the fun times, hard work and some long hours over the year I have been very fortunate to have had 2 wonderful holidays. My Christmas and New Year’s adventures in Mexico with friends and Columbia with my son will be something I will never forget! And then a recent trip to spend time with my daughter and grandchildren, and my Mother and old school friends was also wonderful! This Christmas will be much quieter. Time at home suits me, and perhaps I will get to try all the new recipes I’ve been collecting (such as Christine’s Christmas recipe in this magazine). It seems everyone leaves Auckland at Christmas, so it’s also a good time to enjoy all the things that the Auckland region has to offer and to explore places we haven’t been to yet.

Wishing you all the best for the season and New Year! Ingrid

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**welcome to Robyn.**

We are very pleased to have Robyn O’Connor join our team as a volunteer. Robyn is married to Tom and they have a daughter, Phoebe, who is currently studying at Auckland University. Robyn has taken a year off from her paid work as a Fundraiser but, fortunately for us, she has chosen to share her fundraising expertise in a volunteer capacity.

Due to a remarkable set of circumstances, Robyn saw the MS Auckland advertisement for a Bequest Coordinator on the Volunteering Auckland website. She gave us a call and it became clear very quickly that she was a perfect fit for what MS Auckland was looking for. Robyn has experience as a bequest fundraiser at Hibiscus Hospice and Cancer Society Auckland.

We are enjoying having her and she is enjoying sharing her expertise with us. Robyn tells us that she is looking forward to speaking to MS Auckland supporters over the next few months.

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**a few words from Ingrid.**

*Our General Manager*
events for your calendar.

Upcoming events

Remember the best way to keep in touch regularly with upcoming special events is through our e-newsletter and website.

If you don’t get our monthly e-newsletter you can sign up on our website – www.msakl.org.nz – or you can contact Becky at the office on 09 845 5921 and ask her to put your name down.

Sunday 18th February
Bike the Bridge!

Go to www.bikethebridge.co.nz to register.

This is a once a year opportunity to ride over our Harbour Bridge, enjoy a fun filled day and support MS Auckland with your ride. We’ll be sending out more information on this soon. Mark this day on your calendar!

Sunday 10th December
Annual MS Christmas Party
1pm to 4.30pm

Held at the Remuera Club. Cost of $25/person includes a buffet lunch, music and fun!

Saturday 24th February
Wellness Workshop

Our first workshop of the year will be presented by Auckland Disability Law and will look at Employment Issues. Time: 10am to noon
Venue: Remuera Club

Thank you Jos Pickett.

On the 1st of March 2017, Jos (Josephine) Pickett, a longtime member of MS Auckland passed away peacefully in Auckland City Hospital.

Jos was diagnosed with MS quite late in life at the age of 63. She was very grateful for the support she received from MS Auckland and made generous donations during her lifetime.

Her Field Worker, Georga, remembers Jos as a strong, intelligent lady who had lived an extremely interesting life overseas, and here in NZ.

Jos continues her generous support of MS Auckland with a gift in her Will to ensure people diagnosed with MS in the future receive the support and assistance they need to lead a fulfilling life. In this case Jos’s legacy was to ensure high quality of life to people who shared her diagnosis. The gift Jos left to MS Auckland in her Will, and others like it, is invested to future-proof this charity. We do not know what the world will look like in the future but we do know people with MS deserve the best support MS Auckland can provide. A gift in your Will ensures MS Auckland can meet those needs.

If you would like to make this special gift to MS Auckland, it is important to make sure you specify Multiple Sclerosis Auckland or our charity number CC10863. This will ensure that your gift goes to support the people and families living with MS in the greater Auckland region.

A gift can be a specified amount, or a percentage of your estate. An example of the wording in your will can be: “I give to Multiple Sclerosis Auckland ___% of my estate, OR the rest and residue of my estate, OR the sum of $___ for its general purposes free of all charges. The official receipt of the Treasurer or other authorized officer of MS Auckland shall be a full and sufficient discharge to my executors.”

For more information about how to leave a gift to MS Auckland in your Will, please check our website www.msakl.org.nz, or contact Ingrid or Mark on 09 845 5921 (or Ingrid@msakl.org.nz, or Mark@msakl.org.nz).

If you make the generous decision to help future proof MS Auckland with a gift in your Will we would love to know. Please tell us so we can thank you properly.
Managing stress over the Christmas Holiday period

The season of stress is upon us. Although many people look forward to Christmas, and the holidays, there are those of us who see it as just a time to “get through” and that’s okay.

Unfortunately MS does not take a holiday just because it is Christmas and we all know stress can have a negative effect on MS. Therefore, we need to look at ways of keeping calm and keeping our stress at a manageable level.

Remember a little stress is a relatively normal part of life; however, excessive or long term stress can have a negative effect on our physical and emotional health.

We have put together a list of strategies to hopefully help you reduce stress this Christmas.

• Plan – Make a list of everything you have to do between now and Christmas.
• Prioritise - Mark in red the things you absolutely have to do, your non negotiables. Think hard about what you put on this list, there are some things, you may decide do not really have to be on it. Dump them.
• Pace yourself - Remember, you do not have to do everything yourself. Delegate.
• Learn to say no - Saying yes, when you should say no, can leave you feeling resentful and overwhelmed.
• Stick to a budget - Don’t try and buy happiness with an avalanche of gifts, which you could be paying for well into the New Year.
• Be realistic - Holidays do not have to be perfect.
• Reach out - Christmas can be a lonely time for many people. Seek out community, religious or other social events.
• Acknowledge your feelings - It is okay to feel sadness and grief at this time of year. You can’t force yourself to be happy just because it’s the holiday season. Look at doing things you enjoy and, once again, reach out. Talk to others about how you feel.
• Have an escape plan - Have some pre planned excuses if proceedings get too stressful.
• Don’t abandon healthy habits - Over indulgence only adds to stress and guilt.
• Make time to exercise - Exercise is a great way to reduce stress.
• Get out in the fresh air – There is nothing like being in the outdoors to help the feel good endorphins kick in.

Remember if things don’t go according to plan then you can change the plan. Make the holiday season work for you.

Wishing you all a stress free Christmas break!

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<td>5 The Strand, Takapuna</td>
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<td><a href="mailto:Kirsty@msakl.org.nz">Kirsty@msakl.org.nz</a></td>
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<td>Monday – Friday 9am to 5pm</td>
<td><a href="mailto:Mark@msakl.org.nz">Mark@msakl.org.nz</a></td>
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The office will close on Friday the 22nd of December and re-open on the 8th of January.
From all of the Auckland Hospital MS team, have a very happy holiday and we wish you all the best for 2018!
Robert was featured in the June magazine with his new Freedom Chair. The chair has changed his life, giving him back so much freedom and allowing him to get out and go places he probably wouldn’t have ventured to in his old chair. At the end of the story Robert mentioned that they were heading to Europe at the end of July and that they will be taking the new chair with them.

I wanted to find out more about their recent trip to Europe and how it all went, so I arranged to meet with Robert and Sharon in their lovely home in West Auckland. Somehow conversation got around to the early days of Robert’s MS with Sharon telling us the story of how he finally got diagnosed. It’s a sad story that unfortunately may be familiar to some of you…..

Robert was about 50 years of age when Sharon started noticing that he was losing his balance a lot. They used to enjoy walking along the rocks on the beach, but Robert started finding this very difficult. Playing tennis, another thing that Robert enjoyed, was also getting difficult. Robert was a Sales Rep and spent many hours on the road. He loved his job, but even driving was getting harder as he was finding his vision was doing strange things. He was also experiencing headaches and migraines.

They would go to the doctor only to be told ‘you are not as young as you used to be’, and somehow putting all the symptoms down to aging! Sharon would argue with the doctors, to no avail. She knew that there was something wrong.

Perhaps the turning point was after a business meeting with a client. Robert got up to leave the café and fell flat on his face. People around thought he must be drunk!

Robert ended up in hospital. They initially thought the problem was in his spine. Once again it was at Sharon’s insistence that Robert have an MRI that finally got him one, but it was only on his spine, which showed up perfectly fine. Robert stayed in hospital and Sharon continued to ask for an MRI of the brain. Finally they listened! The MRI showed multiple lesions and MS was finally diagnosed.

Unfortunately Robert could no longer work. Over the years it seems that MS has touched every part of his body. Sharon also gave up her work to become Robert’s full time carer. Robert speaks fondly of Sharon and the two are obviously very close. “I don’t know what I would do without her”, says Robert, “she does everything for me”. One week a month Robert goes to Laura Ferguson, to give Sharon a bit of a break. He enjoys catching up with his friends and having coffees in Newmarket. Sharon says that she misses Robert when he goes.

The trip to Europe was amazing. They went with their son and stayed with their daughter and her family in Germany. “There is no place this chair won’t go”, says Robert. The highlight perhaps was the trip to Heidelberg Castle. Robert was able to go wander (in the chair) throughout the castle, as well as all through the cobblestone streets of the area.

I looked through their beautiful photographs of the trip as both Robert and Sharon reflected on the lovely memories of their family holiday. Afterwards we went out on the deck for a few photos and then I had to be on my way. Thank you Robert and Sharon for a lovely morning!
I’m the fittest I have ever been.

*Megan Marshall - NZ Invictus Games Team Member*

Megan is a logistics specialist in the Royal New Zealand Air Force. She has had MS since 2009. In September this year she participated in the Invictus Games in Toronto. You may have seen her story in the Attitude video that we also placed on our facebook page (www.facebook.com/multiplesclerosisakl/).

What are the Invictus Games? They are an international adaptive multi-sport event, created by Prince Harry, in which wounded, injured or sick armed services personnel and their associated veterans take part in 12 different adaptive sports.

Megan, along with 24 other people from across the country, represented NZ at the games. Megan can’t remember how she found out about them or what triggered her to try out for it, but she thinks it was probably from an article featuring previous athletes in one of the Air Force magazines. She admits to being terrified to apply. It must have been important to her though, as eventually she did apply and she got accepted!

Megan faced her big fear of rejection when she applied to be on the team of the Invictus Games, but she also faced another one of her monsters – MS! Megan struggled with her diagnosis and never really faced up to it mentally. She found that no one around her really understood what she was going through and she felt very alone and isolated with an unpredictable condition that could leave her at times feeling both mentally and physically debilitated.

Once accepted onto the Invictus Team, serious training began. Megan entered to participate in two of the events – Power Lifting and Indoor Rowing. She loved the training. Being in the gym made her forget she had MS. Through the year they also had 4 training camps when she got to meet up and train with all the other competing athletes.

When I say the word ‘athlete’ to Megan she laughs. “I never thought of myself as an athlete” she says. And when I tell her what an ‘inspiration’ she is to others she shakes her head in disbelief. “Never would I see myself as being inspiring to others”.

The trip to Toronto for the games Megan describes as a ‘mind-blowing experience’. Fortunately her husband and her parents were able to join her. The whole experience was a massive learning for Megan. There was a fair bit of stress involved too, especially when they found themselves on the wrong bus to her Power Lifting event and then having to have police escort back to the venue so that she could still make it in time to participate, with just minutes to spare!

Training is still very much a part of Megan’s life now and she proudly states “I’m the fittest I have ever been”. The games changed Megan in other ways too. She feels now that for the first time, since her diagnosis eight years ago, she can accept her MS and she can talk about it with others. “I’m so much better now due to being part of the Invictus Team”, she says.

Other than exercise, Megan manages her MS with Tysabri infusions, a good diet, and a good mental attitude.

We are so proud of you, Megan! You are indeed a most inspiring athlete!
This lovely recipe comes from Christine, whose husband, Kevin, was diagnosed with a Primary Progressive form of MS. Christine writes, “Our approach became one of not ‘having’ MS but one of ‘living’ with MS and working positively with all that one's body is willing and able to do through eating wisely, exercising regularly, and the power of positive thinking, including meditation”.

Christine and Kevin began integrating the Jelinek diet into their lifestyle in 2007 when George Jelinek ran his first New Zealand retreat on the Coromandel.

Christine writes - The Jelinek Diet has been relatively easy to incorporate into our eating and we have approached it through first eliminating the foods / products to avoid and concentrating on the range of foods / products that are compliant. We have always enjoyed eating fish which brings added choice and flexibility. Our extended family and close friends are aware of Kevin's dietary needs and enjoy the challenge of finding and adapting recipes. There is certainly universal ‘buy in’ that whatever diet compliant food is prepared is good eating for us all.

A recent trip to country towns in Northern France was made so much easier through using Google Translate and listing food components we were trying to avoid e.g. ‘dairy free – sans produits laitiers’.

The key for us as a family has not been to focus on the Jelinek Diet in isolation but to incorporate it into living well.

**Puy lentils, quinoa, pomegranate, roast grapes and tomatoes, chilli, mint and basil**

This is a recipe from Bite (NZ Herald) which involves some multi-tasking but is worth the effort. The dish is Jelinek Diet friendly. It serves 6 as a starter or can be a delicious side dish to salmon (150g per person)

**Here is what you need...**

- 200g (2 cups) Black and green grapes
- 200g cherry tomatoes (use several colours)
- 1 banana shallot thinly sliced
- ½ medium red chilli (take seeds out for milder)
- 2Tbsp pomegranate molasses
- 4Tbsp extra virgin oil or use rice bran oil
- 200g (1 cup) puy lentils, rinsed and drained
- 4 garlic cloves, sliced
- 1 tsp finely chopped thyme leaves
- 1 tsp finely chopped rosemary leaves
- 1 tsp finely chopped oregano leaves
- 1 bay leaf
- 150g (1 cup) quinoa, rinsed and drained
- 1 handful of parsley leaves
- 30 mint leaves
- 20 basil leaves
Here is what you do
Heat the oven to 170C

The roasting part
Put the grapes, cherry tomatoes, shallot, chilli, pomegranate molasses and 2 tablespoons of the oil in a roasting dish with a little salt and pepper. Stir together then roast until the grapes and cherry tomatoes have popped a little – about 30 minutes. Keep warm.

The lentils
Meanwhile cook the lentils in a medium saucepan with enough water to cover by 4cm. Bring to the boil, skimming any foam that rises to the surface. Reduce the heat to a rapid simmer then stir in the garlic, thyme, rosemary, oregano, bay leaf and the remaining 2 tablespoons of oil, adding 1 teaspoon of flaky salt in the last 10 minutes.

Don’t let the water level fall below the surface of the lentils: top up with a little boiling water if needed. Keep warm.

The Quinoa
When the lentils have been cooking for about 15 minutes, cook the quinoa. Bring 1 litre of water to the boil in a large pan and add the quinoa.

Cook for 9-12 minutes by which time the quinoa will still have a little bite but will have softened in texture. Drain in a fine sieve and leave to cool.

To serve
- Toss the lentils and quinoa with the parsley and mint. Taste for seasoning
- Mix the basil gently into the grapes and cherry tomatoes and this sits on top of the lentil / quinoa mix
- Drizzle the roasting juices over the dish
- Serve at room temperature

For more information on the Jelinek diet go to https://overcomingms.org
Dr Jennifer Pereira.

Jennifer Pereira is one of MS Auckland’s very kind patrons. We all know Jennifer for the time, the dedication and the passion that she has for MS and the people under her care. She never hesitates to give us her time voluntarily to help with newly diagnosed days or research day. I asked her for an interview, to try to find out a wee bit more about her, and was thrilled when she happily obliged!

Interview by Ingrid Minett

Tell us a bit about yourself...

I grew up in Auckland but also spent some of my teenage years in Montreal, Canada. Both of my parents are retired doctors - my father was an immunologist and my mother a general practitioner. I went to Auckland Girls Grammar School and then across Grafton Bridge to Auckland Medical School and over the road to Auckland City Hospital where I am now working as a Neurologist in the Department of Neurology. I completed most of my Advanced Training in Neurology at Auckland Hospital and spent just over a year in the UK to complete a fellowship in MS.

Just before I left for the UK I met my now husband. We are very lucky to have two beautiful daughters. They are 5 and 7 now and certainly keep both of us on our toes!

How long have you been a neurologist and what made you decide to become a neurologist?

I graduated from medical school in 1997 and so have been a doctor for 20 years now! I have been a neurologist for 9 years. Determining the cause for patients’ neurological symptoms and helping them to understand this, combined with a fascination for the function of the brain is what led me to a career in neurology.

Why did you decide to specialise in MS?

I have always had an interest in the immune system – likely thanks to an earlier exposure to the enthusiasm of my father. I remember sitting through dinner table discussions about antibodies. During my medical training I spent six months in oncology and was fascinated by the concept of paraneoplastic central nervous system disease. This is where a cancer in the body leads to an autoimmune disease in the brain or spinal cord. This then led to a subspecialisation in neuroimmunology of which MS is the most common condition.

What are some of the main questions that come up for people when they are newly diagnosed?

The most common questions are around the cause and treatments of MS. Most people want to understand what the diagnosis means for their future as they often will know someone with MS and wonder if MS will impact on their life in the same way.

What do you see as some of the biggest advances in MS care since you have been practicing?

The new MS therapies for patients with RRMS that we have had in New Zealand since November 2014 have made a big difference to the MS clinic. In the RRMS population we are no long spending as much time treating relapses and much more time starting and monitoring the new therapies.

What do you see as some of the main challenges that are still being faced in MS care?

I see the current main challenge is to better understand the complex cause of progressive MS and how to best treat this.
How do you see the future of MS care for people in NZ and worldwide?

I think the latest results of the ocrelizumab trials showing benefit in primary progressive disease is a positive step towards treatment in this population. I am optimistic that at some point medications that can lead to repair or remyelination of damaged nerves will be possible.

What will you be doing these Christmas holidays?

I am having some time off as we are planning a family trip up north which, weather permitting, will include camping at the beach.

Thank you, Jennifer! I will keep my fingers crossed that you have wonderful sunny days for some memorable family times camping on the beach!

volunteer profile.

Written by Becky Tucker, Volunteer and Admin Assistant

Tonia’s warm hearted nature welcomes any newcomers to the group making them feel right at home. It’s no wonder this group is well attended with many partners coming along too. Support groups are a fundamental part of our MS Community. For the ‘roaming west’ group (also known as the Kumeu support group) it’s not only a good excuse to try all the lovely cafes in the area, it’s a chance for people to get together to chat, share stories and pick up all sorts of tips on the way.

MS Auckland is very thankful for Tonia’s huge contribution in the initiation and the smooth running of the Support Group.

I would also like to acknowledge all our volunteers at this time. Without your help we would not be able to offer all that we do.

Our volunteer profile this December is Tonia Matthews - a lady with a big heart who enjoys giving back to the community. Tonia has been our Support Group Co-ordinator for the West for the past 7 years.

Tonia’s son has MS, so she knows only too well the importance of having a good support network for people living with MS. So with some help from the Field Worker 7 years ago, they set up the ‘roaming west’ support group. Every month a venue is chosen, which Tonia organises and attends. She also drives those that need a lift.

“We make a living by what we get, but we make a life by what we give.” — Winston Churchill

Tonia Matthews

Some of the members of the Kumeu Support Group
book review.

Donald Bowie reviews ‘When the Body says No’ by Gabor Mate

I am happily experiencing Primary Progressive Multiple Sclerosis (PPMS) and consider myself a participant in the journey which is our life together – PPMS and me. By all accounts we will not be parted and therefore I am interested in learning as much as possible about the implications for our time together and how to achieve three goals: 1. maximise the opportunity, 2. minimise the disruption and 3. live a full and enjoyable life.

My search for information led me to this book by Canadian doctor, Gabor Mate. He presents an interesting spin on a range of diseases including arthritis and cancer, and with a chapter on MS.

The Central Theme
I read Mate’s book to explore a realm of thinking about disease my doctors didn’t discuss with me but which I think is logical. The interdependencies and interconnections between the environments in which we live, our biological metabolism, our neurological network and our mind and thoughts is the central theme of the book, one I was keen to explore as I did not think these can be viewed and ‘treated’ separately.

After reading Mate’s proposition and explanation that patients of chronic illnesses may have had dysfunctional family relationships during their upbringing, I reflected on two high-stress events in my life that preceded the development and acceleration of my own MS symptoms – declining balance, deteriorating control of my left limbs, progressive tingling on my back and growing tiredness. Whether these two events are symptomatic of a stressful upbringing I can’t say but the book has caused me to reflect on my life and how I might change things.

Pick up and put down
I didn’t read When the Body Says No from go to whoa; I tended to pick it up, read a bit and then reflect on what I had read. Each chapter stands alone but you need to read the first couple of chapters to understand Mate’s hypothesis. I was not always able to fully understand all of Mate’s thesis but found the stories of his patient’s experiences helpful to explain the theory. Most of the stories tied Mate’s hypothesis back to the patients’ emotional state of being during their upbringing and their family relationships.

Mate linked his patient’s familial progression and consequential sociological development which he felt led to the subsequent repression of feelings (of all types). That, in turn, affected on the patient’s “interpersonal biology” predisposing them to a chronic disease.

Throughout the book Mate bases his case on certain personality types and their expression of emotions illustrated by references to his own patients’ medical histories and supporting research. These stories provide an interesting human aspect to what could be quite a dry topic. Through them I could relate to situations I had experienced and reflect on whether they applied to my life.

Contributing factors
Mate’s point of view matches my own belief that my condition is a consequence of a number of contributing factors. While Mate’s book has given me some insights on how my MS may have arisen, nothing in the book tells me how I could turn back time and, maybe, change things. Can anyone other than history writers do this?

From reading the book, I do have a better understanding of how our upbringing and the emotional baggage we carry might contribute to the development of a systemic disease. And the book has caused me to think. I did reflect at length on whether I shared any of the influences Mate identified but couldn’t identify anything specific. I don’t know whether I could or would have done anything differently in the past to change my future and the progression of the disease.

Informative read
If you’re interested in the theory that disease is a consequence of many factors and would like to better understand the possible impact of emotional stress on the development of chronic diseases then this is an informative read.
Medical Cannabis Awareness New Zealand (MCANZ) is New Zealand’s only Registered charity devoted exclusively to tackling the “C word” to gain access for patients. As the condition with the most benefit MCANZ has put an extensive focus on the plight of MS patients due to the cost of Sativex.

Much of this effort is around alternative Medical Cannabis products, where there is potential to find cheaper products that may perform as well, or perhaps even better than Sativex at a reduced cost to the patient.

In late 2016 MCANZ had its first success with the Non Pharmaceutical application scheme, and Auckland Woman Dr Huhana Hickey MNZM was New Zealand’s first patient to successfully trial a non-pharmaceutical product “I found the Tilray Oil more pleasant to use, it gave me my quality of life back” Says Dr Hickey The process is not without its flaws however, and from the beginning of our advocacy to the eventual arrival of product it took over 9 months.

Eclipsing this long wait, is our advocacy for Helen Old of New Plymouth, due to the rural locale and long lead times to see specialists, it took a year of advocacy to get an approval for a new, more affordable product. Helen has endured with MS for a long time, she was initially diagnosed with secondary progressive MS in 1985 at the age of 24, despite this Helen has continued to live life fully, and had a daughter Jessica.

In the last few years Helen’s mobility has decreased as her pain increased, and after trying a battery of prescription medicines to treat her pain, her family resorted to trialling cannabis illicitly, with the express desire to confirm it works before investing the required time and effort into obtaining a legal supply. Helen found significant improvement in her pain and spasticity and fatigue, which restored her ability to have a social life. “we noticed the difference in 2 days, spasms basically stopped, and pain in particular was improved by perhaps 75%. The amazing thing was Helen had the Energy and the desire to go out in public and socialise outside of the house.” Says Helen’s husband Peter.

Following from this, after 12 months of advocacy and support from MCANZ, Helen was approved for a new product that MCANZ predicts will be half the cost of Sativex once imported, another degree more affordable than Tilray. Helen was the first New Zealander to be approved for 2 Cannabis based products, and the first to be approved for a high THC Oil. The hope is by combining the 2 treatments as separate “daytime” and “night time” oils Helen will get the best of both worlds, with the best trade-off between relief from pain and spasticity versus sedation during the day, and something a stronger in the evenings to enable a better night’s sleep.

These products are likely to be more tolerable due to their nature, as they are an olive oil based liquid to be used from a dropper, as opposed to the spray form of Sativex which some patients find irritating enough that it prevents continuing treatment.

MCANZ is putting a lot of effort into MS patients with these new products under the Non-pharmaceutical pathway, and the Ministry of health has not turned down an application yet, with 100% success rates, the barrier is cost, which has been appreciably lowered with these new products, and the final barrier is prescribers.

If you are interested in trialling Medical Cannabis or want to know more please register here http://mcawarenessnz.org/sign-up/
With natural disasters happening on a regular basis throughout New Zealand, you’ve probably all wondered at some point, what would happen to you if a natural disaster struck in Auckland. In Auckland, we all know it’s a case of ‘when,’ not ‘if,’ although I’m sure we would all like to hope that it won’t happen in our lifetimes! We do live on a Volcanic Field in the Shaky Isles, so being prepared is the smart thing to do. It will give you the best chance of survival in the event of an emergency!

Everyone should have their disaster survival and getaway kits ready, in their homes, at work and in their cars, as applicable. Everyone should also have a household emergency plan. Websites such as www.getthru.govt.nz and www.prepare.co.nz have great tips, checklists and materials to help you to do this.

But when you have a chronic illness or disability, there are extra considerations to make when preparing for a disaster. Here I summarise and elaborate on the tips given at getthru.govt.nz. To read the full recommendations visit the following web address (especially if you want more detailed information for those with hearing or sight impairments): http://www.getthru.govt.nz/how-to-get-ready/people-with-disabilities/

Preparing:
The first thing to do to prepare is to create a social network so that you are not alone when a disaster strikes. Choose some key support people who will agree to help you in the event of an evacuation, especially if you are not physically able to get out on your own. These people may be your neighbours, carers or some family or friends who live close by, but make sure they always know if you are going to be away from the house or on holiday. Have them agree to help you to evacuate so that you are not left stranded in an emergency. If you use mobility aids or a wheelchair, you may have more than one person agree to carry you out of the house, in the event that there is no clear pathway for your mobility aids, but if you are able to take mobility aids with you, make sure your support people know how to use them. Make an evacuation plan in advance, attempting to think of everything that could go wrong and practice it with these key people so that you know what to do in an emergency.

Secondly, once you have made your standard survival and getaway kits, you will want to add on anything extra that you will need as a result of your illness or disability. This could be spare mobility aids, a minimum of 7 days supply of all of your key medications, cooling methods (E.g. chilly bin and ice) for any items requiring chilling, key medical records and alert tags or bracelets, non perishable food items for special dietary requirements, assistive devices for opening food items such as cans and anything else you can think of that you may need if you have to leave in a hurry. Have them all in one place that’s easy for you or someone else to grab in the event of an emergency.

Evacuating:
In the case that you have to evacuate in a hurry, plan with your chosen support people where you will go and think about the following questions:

- Can your mobility aids and evacuation kits fit in the vehicle with you and your support person or people? Remember that they will need their own emergency kits too!
- Will you go North, South, East or West?
- What if the route to your first choice of location is blocked off….what is plan B?
- Where will you plan to stay?
- Can you physically manage staying in an evacuation centre?
- If not, is there a hotel or motel where you can befriend staff and let them know that you plan to stay in the event of an emergency? Let them know of your needs in advance. Or perhaps you have a friend or family member out of Auckland that may be able to help?
- Do you require any life-sustaining or life-saving equipment or treatment?
- If so, do you know where the best place to go is?
Talk to your key specialist and find out where to go in the event of an emergency, especially if you need medical treatment!

- If you have a hearing impairment, make sure your chosen support people know to alert you when there is an emergency, especially if you are unable to listen to radio updates. Have them agree to alert you to key warnings and updates and discuss the method by which they will do this. It could be that they agree to send you a text message, but if phone systems are down, you might want to consider giving your key support people a house key so that they can let themselves in to help you.

**What if there is an earthquake and I can’t move?**

GetThru.govt.nz states that “in a major earthquake, the ground-shaking will make it difficult or impossible for you to move any distance.” It is even more difficult with a physical disability or mobility impairment. If you’re not able to get underneath a table, the best thing to do is to go as near as possible to an inside wall of your house, away from windows and tall or loose items that may fall or smash on you. Make sure you cover your head and neck as best as you can, even if you only have your arms to protect them. For wheelchair users, make sure you lock your wheels and/or put the brakes on. If you are in bed, pull the blankets and sheets over you and use your pillow as protection for your head and neck.

For more information, there is a “Drop cover and hold” information sheet for people with physical disabilities and mobility impairments that can be downloaded from the GetThru website link shared above for people with disabilities.

**Take Action:**

Lastly, I know that many of us have the tendency to put this off, thinking it will never happen to us. But that’s what the people of Christchurch and Kaikoura likely thought, and look what happened there! If a disaster struck tomorrow, would you be ready? I sure hope so! Perhaps make it your New Year’s Resolution to have your disaster kit ready. If it’s too overwhelming to prepare your disaster kit all at once, I challenge you to buy 1-5 items for your emergency kit every week! Print out a checklist from the two websites mentioned at the beginning of this article, and give it a go, checking off the items one by one! What have you got to lose?

Be safe everyone and I leave you with this perfect phrase to ponder on in regards to procrastination:

“One of these days is none of these days”

*There’s no time like the present!*

---

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**OR**

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Web: www.freedom-chair.nz
It is wonderful to see the interest in the hydrotherapy continuing and the benefits being continued to be enjoyed. Hydrotherapy is more than ‘water-walking’. It is a whole body workout that uses high intensity training combined with low intensity rest periods. The benefits of hydrotherapy for people with MS includes – improved muscle strength, improved fitness, improved gait and mobility, reduced fatigue, and increased quality of life and send of well-being!

Anyone with MS can try two sessions at no cost before deciding on whether they want to continue regularly. If you haven’t tried it yet, then we highly recommend you talk to your Field Workers about it and consider giving it a go! If you don’t have a Field Worker call the office on 09 845 5921 or e-mail us at info@msakl.org.nz and we’ll link you in with the Field Worker in your area.

We take a bit of a break over the holiday period. Please note the holiday hours below:

**Hydrotherapy Christmas Closures and New Year Openings**

<table>
<thead>
<tr>
<th>Pool</th>
<th>Final 2017 Class</th>
<th>First 2018 Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lloyd Elsmore Pool</td>
<td>Tuesday 5 December</td>
<td>Tuesday 13 February</td>
</tr>
<tr>
<td>Millennium Pool</td>
<td>Wednesday 13 December</td>
<td>Wednesday 14 February</td>
</tr>
<tr>
<td>Manurewa Pool</td>
<td>Wednesday 13 December</td>
<td>Wednesday 14 February</td>
</tr>
<tr>
<td>Epsom Pool</td>
<td>Thursday 14 December</td>
<td>Thursday 15 February</td>
</tr>
<tr>
<td>Westwave Aquatics</td>
<td>Friday 1 December</td>
<td>Friday 16 February</td>
</tr>
<tr>
<td>Diocesan Girls Pool</td>
<td>Saturday 16 December</td>
<td>Saturday 10 February</td>
</tr>
</tbody>
</table>

**2017 Weekly Sessions**

<table>
<thead>
<tr>
<th>Pool</th>
<th>Days</th>
<th>Time</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lloyd Elsmore Pool</td>
<td>Tuesday</td>
<td>11.00am - 12.00 noon</td>
<td>Dianne Bartlett 09 845 5921 Ext 220 <a href="mailto:dianne@msakl.org.nz">dianne@msakl.org.nz</a></td>
</tr>
<tr>
<td>Manurewa Pool</td>
<td>Wednesday</td>
<td>10.30am - 11.30am</td>
<td>Diane Hampton 09 845 5921 Ext 219 <a href="mailto:diane@msakl.org.nz">diane@msakl.org.nz</a></td>
</tr>
<tr>
<td>Epsom Pool</td>
<td>Thursday</td>
<td>10.30am - 11.30am</td>
<td>Carol Andrews 09 845 5921 Ext 222 <a href="mailto:carol@msakl.org.nz">carol@msakl.org.nz</a></td>
</tr>
<tr>
<td>Westwave Aquatics</td>
<td>Friday</td>
<td>11.00am - 12.00 noon</td>
<td>Andrea Kortas 09 845 5921 Ext 221 <a href="mailto:andrea@msakl.org.nz">andrea@msakl.org.nz</a></td>
</tr>
<tr>
<td>Diocesan Girls Pool</td>
<td>Saturday</td>
<td>10.00am - 11.00am</td>
<td>Carol Andrews 09 845 5921 Ext 222 <a href="mailto:carol@msakl.org.nz">carol@msakl.org.nz</a></td>
</tr>
</tbody>
</table>
resistance training may slow down the progression of multiple sclerosis.

The following article was taken from the Science Daily website: https://www.sciencedaily.com/releases/2017/08/170801090231.htm
It was also reprinted in the Neurological Foundation of New Zealand magazine, Headlines, Summer 2017.

In the past, multiple sclerosis patients were advised not to exercise for fear of exacerbating the condition. However, it is now known that physical training can relieve many of the symptoms, including the excessive fatigue and mobility impairments that are often experienced. New research now shows that resistance training may protect the nervous system and thus slow the progression of the disease.

This is the main finding of a study conducted by a research partnership between Aarhus University, Aarhus University Hospital (Denmark), the University of Southern Denmark and the University Medical Center Hamburg-Eppendorf in Germany, that has recently been published in Multiple Sclerosis Journal.

The study shows that resistance training has a number of positive effects on the brain, which go beyond what can be achieved through effective disease-specific medication.

"Over the past six years, we have been pursuing the idea that physical training has effects on more than just the symptoms, and this study provides the first indications that physical exercise may protect the nervous system against the disease," says one of the researchers behind the study, Associate Professor Ulrik Dalgas from the Department of Public Health at Aarhus University.

"For the past 15 years, we have known that physical exercise does not harm people with multiple sclerosis, but instead often has a positive impact on, for example, their ability to walk, their levels of fatigue, their muscle strength and their aerobic capacity, which has otherwise often deteriorated. But the fact that physical training also seems to have a protective effect on the brain in people with multiple sclerosis is new and important knowledge," Dr Dalgas says.

In the study, the researchers followed 35 people with multiple sclerosis for six months. Half of the group engaged in resistance training twice a week, while the other half continued to live their lives normally without systematic training.

Prior to and following the six-month period, the test subjects had their brains MR-scanned, and the researchers could see that there was a tendency for the brain to shrink less in those patients who undertook resistance training.

"Among people with multiple sclerosis, the brain shrinks markedly faster than normal. Drugs can counter this development, but we saw a tendency that training further minimises brain shrinkage in patients already receiving medication. In addition, we saw that several smaller brain areas actually started to grow in response to training," Dr Dalgas says.

The researchers behind the study are still unable to explain why training has a positive effect on the brain in people with multiple sclerosis. Dr Dalgas says that a bigger and more in-depth ongoing study will help to clarify this, and may also lead to improved treatment options. However, he stresses that the aim is not to replace medication with physical training.

"Phasing out drugs in favour of training is not realistic. On the other hand, the study indicates that systematic physical training can be a far more important supplement during treatment than has so far been assumed. This aspect needs to be thoroughly explored."

It is not yet clear whether all people with multiple sclerosis can benefit from this type of exercise, as it has not been sufficiently tested in the more severely affected patients. Therefore, Dr Dalgas is not recommending that all multiple sclerosis patients throw themselves into intensive physical training regimes without first seeking professional advice.
support groups.

MS Support Groups meet throughout Auckland. They are free and open to anyone with MS to come along. It is a great way to meet other people who truly understand what you are going through and to share the type of practical insights that can only come from first-hand experience. If you are interested in starting up a support group, please talk to your Field Worker.

Some groups will not be meeting in December, and all groups will be resuming at different times in January or February. It is best to check in with the Field Worker listed below under ‘Contact’ before heading out to make sure that it is still scheduled to go ahead.

<table>
<thead>
<tr>
<th>Location</th>
<th>Contact</th>
<th>Date/ Time</th>
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</thead>
<tbody>
<tr>
<td><strong>South / East Auckland</strong></td>
<td></td>
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</tr>
<tr>
<td>Beachlands Support Group</td>
<td>Dianne Bartlett</td>
<td>Fridays / Six Weekly 11.30am</td>
</tr>
<tr>
<td>Pepper Jacks Café</td>
<td>021 845 903</td>
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</tr>
<tr>
<td>Pukekohe Café Group</td>
<td>Dianne Bartlett</td>
<td>First Thursday / Month 11.30am</td>
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<tr>
<td>Different Venues</td>
<td>021 845 903</td>
<td></td>
</tr>
<tr>
<td>Botany Café Group</td>
<td>Dianne Bartlett</td>
<td>Third Thursday / Month 11.30am</td>
</tr>
<tr>
<td>Whitcoulls Coffee Lounge</td>
<td>021 845 903</td>
<td></td>
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<tr>
<td>(Botany Town Centre)</td>
<td></td>
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<tr>
<td>Manukau Café Group</td>
<td>Dianne Bartlett</td>
<td>Last Tuesday / Month 10.30am</td>
</tr>
<tr>
<td>Friendship House (Manukau)</td>
<td>021 845 903</td>
<td></td>
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<tr>
<td><strong>Central</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City Evening Group</td>
<td>Carol Andrews</td>
<td>Wednesday / Six Weekly 6.00pm</td>
</tr>
<tr>
<td>Scarecrow Café</td>
<td>021 959 187</td>
<td></td>
</tr>
<tr>
<td>Mt Wellington Café Group</td>
<td>Carol Andrews</td>
<td>Second Saturday / Month 11.00am</td>
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<tr>
<td>Coffee Club on Lunn Avenue</td>
<td>021 959 187</td>
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<tr>
<td>Stonefields Café Group</td>
<td>Carol Andrews</td>
<td>Third Wednesday / Month 10.30am</td>
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<tr>
<td>Stonebake Café (Lunn Avenue,</td>
<td>021 959 187</td>
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<tr>
<td>Mt Wellington)</td>
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<tr>
<td>Onehunga Group</td>
<td>Carol Andrews</td>
<td>Second Tuesday / Month 10.30am</td>
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<tr>
<td>Frolic Café (Manukau Rd, Royal Oak)</td>
<td>021 959 187</td>
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<tr>
<td><strong>West Auckland &amp; Rodney</strong></td>
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<tr>
<td>Kumeu Café Group</td>
<td>Andrea Kortas</td>
<td>First Tuesday / Month 10.30am</td>
</tr>
<tr>
<td>Different Venues</td>
<td>021 959 189</td>
<td></td>
</tr>
<tr>
<td>Henderson Garden Café Group</td>
<td>Andrea Kortas</td>
<td>First Thursday / Month 11.00am</td>
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<tr>
<td>Espresso Garden Café</td>
<td>021 959 189</td>
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<tr>
<td>(inside Mitre 10 Mega, 186 Lincoln Rd)</td>
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<tr>
<td>North Café Groupies</td>
<td>Andrea Kortas</td>
<td>Third Wednesday / Month 10.30am</td>
</tr>
<tr>
<td>Kings Plant Barn (Silverdale)</td>
<td>021 959 189</td>
<td></td>
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<tr>
<td><strong>North Auckland</strong></td>
<td></td>
<td></td>
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<tr>
<td>Mayfield Coffee Morning</td>
<td>Diane Hampton</td>
<td>First Thursday / Month 10.30am</td>
</tr>
<tr>
<td>Kings Plant Barn (1 Forrest Hill Road, Milford)</td>
<td>021 859 187</td>
<td></td>
</tr>
<tr>
<td>Shore Lunch Group</td>
<td>Diane Hampton</td>
<td>Last Wednesday / Bimonthly 12.00 noon</td>
</tr>
<tr>
<td>Palmers Planet Café (cnr Hugh Green Drive/Greville Rd, Albany)</td>
<td>021 859 187</td>
<td></td>
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<tr>
<td>North Shore Café Group</td>
<td>Diane Hampton</td>
<td>First Saturday / Month 12.30pm</td>
</tr>
<tr>
<td>Kings Plant Barn (1 Forrest Hill Road, Milford)</td>
<td>021 859 187</td>
<td></td>
</tr>
</tbody>
</table>
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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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: 

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 ______________________

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 0089939 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.

Fidelity Life Harcourts Cooper & Co

AJ Scott Fund Auckland Council Biogen Blue Sky Community Trust Blue Waters Community Trust COGS Constellation Communities Trust Dragon Community Trust Elsie Steele Trust Foundation North Four Winds Foundation Grassroots Trust Infinity Foundation John Ilott Charitable Trust Lion Foundation Lottery Grants Board Lou and Iris Fisher Charitable Trust Louisa and Patrick Emmett Murphy Foundation Lynch Phibbs & Associates Maurice Paykel Charitable Trust Milestone Foundation Ministry of Social Development Mt Wellington Foundation North and South Trust North Shore Presbyterian Hospital Trust Novartis Pharmaceuticals Pelorus Trust Perpetual Guardian Pub Charity Limited Rehabilitation Welfare Trust Rob Webber & Associates Roche Rod Milner Motors Sanofi Seqirus Sir John Logan Campbell Residuary Estate The Southern Trust The Strathlachlan Fund 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
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).