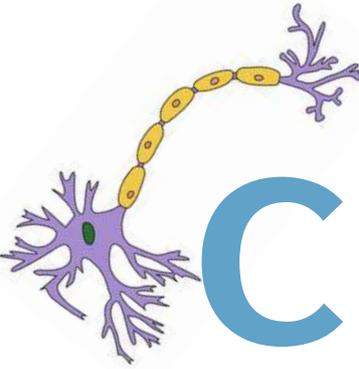




Short Circuit



Developing a national approach to managing assistance animals.

The Commonwealth, state and territory governments are working together to develop options for a nationally consistent approach to the regulation and accreditation of assistance animals. Public consultation (via a survey) is currently underway to improve certainty for people with disability using assistance animals.

..continued page 3



Optimal or Not?

The study, "Impact of previous disease-modifying treatment on effectiveness and safety outcomes, among patients with multiple sclerosis

(Page 7)



Nessie Hunter

Loch Ness is a deep freshwater lake approximately 10 kilometres to the southwest of Inverness Scotland.

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Pilates Trial for Men

Pilates, done regularly, can significantly improve balance and posture in men with multiple sclerosis (MS)

(Page 5)





Armchair Traveller - Nessie Hunter

As we spend another edition of Short Circuit waiting for the day when travel means airports and planes, we will just have to settle back in our armchairs, malt whisky in hand (kilts optional) and go off to the Scottish Highlands. More specifically to the Highland region of Inverness, where the average temperature in Summer is only just a bit warmer than a Winter day in Melbourne. It is here in this wild land we find Loch Ness.

Loch Ness is a deep freshwater lake approximately 10 kilometres to the southwest of Inverness. At 52kmsq, and 230 metres deep, 37 km long, it is the largest by volume in the British Isles and the second deepest in Scotland. Loch Ness is also known as the home of the fabled Loch Ness Monster. There are various villages dotted along the banks of the loch. One of these villages is Dores.

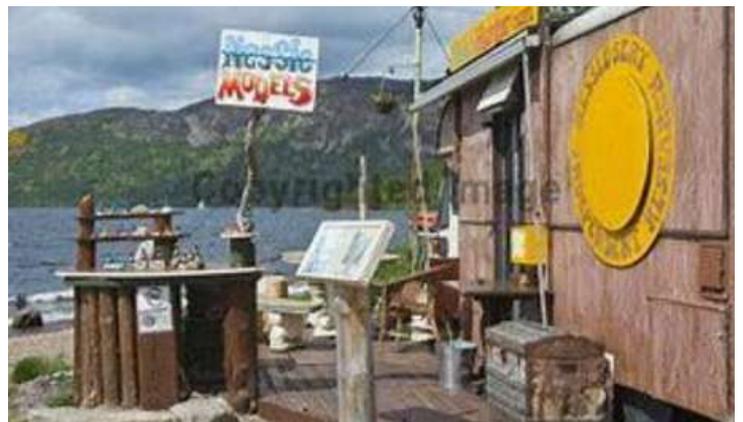


Many people over time have taken an interest in tales of "Nessie". As early as the 6th century AD reports of attacks by a "water beast" in the area became the tale of a miracle, when Irish monk St Columba ordered the beast to not attack one of his followers, who was ironically sent into water by the monk to see if there was a beast. Such stories were disputed as exaggerated tales of the believers. In contemporary times however, sightings and expeditions costing millions of pounds

searched the loch vying to be the first to provide proof of the creature. One such person who became swept up in the pursuit is Steve Feltham. It was during a family holiday to Loch Ness where the seven-year-old Steve would watch men searching for the monster on their vacations. Steve's father seeing his interest, gave him an information folder containing copies of sightings, reports, photographs, sonar charts and maps.

This childhood interest was to stay with him and finally in 1991, Steve sold up and purchased an old bus and set about converting it into a mobile home. Leaving everything behind, he ventured to Loch Ness, determined to prove the sceptics wrong and not knowing how long it would take. Steve's journey was to become the subject of a BBC documentary and he is recognized by The Guinness Book of World Records as the longest vigil to hunt the Loch Ness Monster.

Steve's home on wheels was to settle by the side of the Loch in the village of Dores, opposite the Dores Inn. And after 30 years did Steve ever find the monster? Perhaps not, perhaps it never existed? However, Steve's journey has made him famously known as the Nessie Hunter and become a tourist attraction himself.



<https://www.nessiehunter.co.uk/>



Developing a national approach to managing assistance animals.

Assistance Animals – Developing a Nationally Consistent Approach

The Commonwealth, state and territory governments are working together to develop options for a nationally consistent approach to the regulation and accreditation of assistance animals. Public consultation (via a survey) was conducted to improve certainty for people with disability using assistance animals.

The Department of Social Services sought views of organisations and individuals involved with assistance animals. This included:

- assistance animal training organisations
- assistance animal trainers
- disability peak bodies
- service providers
- people living with disability
- carers, family members or friends of people with disability
- advocates for people with disability
- people who work for a disability organisation
- any other interested parties.

The information and insights provided through the survey was used to inform options for the development of a nationally consistent approach to the regulation and accreditation of assistance animals.



Presidents Letter

Autumn 2021

I hope many of you watched our on-line conference presentation on Saturday 1st May. We had four excellent speakers Nicola Beswick, financial planner and Raylene Carnie, financial counsellor; Helmut Butzkeuven, Head of Department of Neuroscience, Central Clinical School, Monash University, and Director of Neurology at Alfred Health; and John Blewonski, CEO of MS Ltd.

Nicola and Raylene spoke about the difference between advisors and counsellors and the types and sources of assistance that is available to help you manage your money and avoid getting into difficulties or to help you get out of difficulty. They provided a list of organisations available to help and the types of help they can offer.

Refer to page 6 for details.

In addition to the information on Page 6, it's noteworthy that MS has developed a partnership arrangement with the Pro Bono Financial Advice Network (PFAN) which will connect financial advisers willing to provide pro bono advice to Australians in times of financial hardship, specifically a personal health crises such as a diagnosis of MS. Advisers will work with people with MS to improve their understanding of financial issues and to help give them peace of mind about their financial future. More information can be found on their website.

<https://www.afa.asn.au/membership/pro-bono-financial-advice-network>

Helmut Butzkeuven spoke about MS research and the remarkable progress which has been achieved over the past ten years in treatments especially for relapsing/remitting MS. He then discussed some of the reasons why there has not been the same progress in treatments for progressive MS. He suggested this is in part due to the difficulty, (and huge costs involved), in measuring whether a potential new drug will be effective against progressive MS. Helmut then discussed some

exciting new ideas about the use of digital technology, (especially mobile phones), to measure changes in mobility and cognition and how this might speed up the time taken to assess the effectiveness of new drugs and hence make the process more viable.

John Blewonski described how MS as an organisation has become more customer focussed and what this means by way of improved and expanded services. MS recognises that clients at different stages on their MS journey have different needs.

These varying needs are being and will be met by new technology; recruiting staff to meet the demand for allied health and information services; by providing additional physical and virtual service hubs; and by building partnerships with like organisations. Finally, John described the progress being made on new Wellbeing Centres in Sydney and Canberra and plans for additional service hubs in Newcastle and Footscray.

Overall, the speakers conveyed a sense of support, progress, and expectation. My thanks go to the speakers, and to MS for its support, and to the federal Department of Social Services for its financial support in the form of a grant.

Please note that any questions which were not addressed during the conference have been forwarded to the speakers for their attention.

There was a good deal of discussion between presentations about the NDIS proposal to introduce independent assessments, with all expressing some concern. The consultation period for this proposal finished on February 23rd and the National Disability Insurance Agency has published its findings at; <https://www.ndis.gov.au/community/we-listened>.

However, you can still send information and questions to the NDIA at feedback@ndis.gov.au. It is important that we keep reminding them of our concerns.

Study Finds Pilates Helps Men with MS Gain in Balance

Pilates, done regularly, can significantly improve balance and posture in men with multiple sclerosis (MS), helping them to avoid falls and the injuries they can bring, a small randomized trial in Iran reports.

The study, “Effect of Twelve weeks Pilates training on functional balance of male patients with Multiple Sclerosis: Randomized controlled trial,” was published in the *Journal of Bodywork & Movement Therapies*.

Difficulties with maintaining balance and controlling posture are common to MS patients, raising a risk of falls that encourages a more sedentary lifestyle.



Yet, regular exercise and physical activity have multiple health benefits for these patients, from increasing muscle strength and flexibility, to helping with cardiac health, mental well-being, and fatigue.

Pilates done on a mat is low impact, and works to strengthen groups of muscles. Designed to help people with injuries or with a limited capacity for exercise, it improves balance, posture, and a person’s range of motion with regular practice.

Researchers in Iran, along with colleagues in Denmark and New Zealand, conducted a small clinical trial (UMIN000038431) to evaluate whether Pilates might improve balance in MS patients.

Balance, the study noted, is “a complex motor skill which defines the postural dynamics of the body, which is important for preventing falls ... [and] strength-based exercises can play a role in improving balance abilities and can be conducted to improve postural malalignment because they are directly connected to health.”

A total of 30 male patients (mean age, 31.4) were enrolled and randomly assigned, 1:1, to either Pilates training three times per week for 12 weeks, or to no exercise as a control group.

Patients in both groups had significant disabilities, as indicated by a mean score of 4.55 in the Expanded Disability Status Scale (EDSS), which quantifies disability on a scale ranging from one (no disability) to 10 (severe disability leading to death).

The Pilates training program consisted of 60-minute sessions with exercises focused on spinal extension, abdominal strengthening, core stabilization, and postural correction. Each session gradually increased in difficulty, from beginner to an advanced level, based on an individual’s ability to progress.

Each session started with a 10-minute warmup, followed by 45 minutes of Pilates and then five minutes of stretching to cool down.

Changes in balance and posture over the 12-weeks of training were determined using three distinct measures: the Berg’s Balance Scale (BBS), which assesses postural control by having patients perform tasks such as standing up on a chair or standing with closed eyes; the Timed Up and Go (TUG), which measures the time it takes for a patient to stand up from a chair, walk three meters, turn around and sit on the chair again; and the Functional Reach Test (FRT), which measures the maximum distance a patient can reach forward while standing in a fixed position.

While TUG is designed to measure balance, mobility, ability to walk and risk of falling, FRT evaluates dynamic balance.

Patients in the Pilates group showed significant improvements in all three scores over these three months. Their BBS scores increased significantly from 46.8 to 50.60 points; TUG scores decreased significantly (meaning patients were faster at this task), from 11.7 to 9.8 seconds; and the FRT scores rose from 30.1 to 38.2 cm.

In contrast, those in the control group showed no significant changes in posture and balance over this same period, with a tendency toward worsening BBS and FRT scores.

A comparison between the two groups showed that balance and postural measures were significantly better in the Pilates group after the 12 weeks of training.

BUILDING FINANCIAL RESILIENCE

USEFUL CONTACTS & WEBSITES

National Debt Helpline

- Free confidential and independent advice if you are having difficulty managing your debts/financial commitments.
- Initial conversation over the phone with a financial counsellor with the option to be referred to a local service in your area.

Phone: 1800 007 007

Monday – Friday 9.30am – 4.30pm

Live Chat also available via website

<https://www.ndh.org.au/talk-to-a-financial-counsellor/>

Small Business Debt Helpline

- Offers a free and independent service for small businesses and sole traders experiencing financial difficulty. Phone: 1800 413 828

<https://www.smallbusinessbushfire.org.au/>

MoneySmart Website

- A trusted government website committed to helping Australians of all ages, backgrounds and incomes to increase their financial wellbeing and build a better life.
- This website aims to encourage saving; provides simple steps for people who feel stressed and overwhelmed by money and provides valuable information about the use of financial products and services.
- Useful information about how to choose a financial adviser and a link to registered financial advisers in your area.
- Provides a range of tools and calculators to assist in how to budget your money and how to track your spending plus many more useful tools.
- Provides template letters in how to apply for financial hardship

<https://moneysmart.gov.au/>

<https://moneysmart.gov.au/managing-debt>

<https://moneysmart.gov.au/financial-advice/choosing-a-financial-adviser>

<https://moneysmart.gov.au/budgeting/how-to-do-a-budget>

<https://moneysmart.gov.au/budgeting/track-your-spending>

Services Australia

Guide to Government payments, benefits and concessions

- A government website that provides information about social and health payments and services for individuals delivered through Medicare, Centrelink and Child Support.

Centrelink Payment and Service Finder Financial Information Service

- Provides a range of helpful webinars on a cross section of financial topics.

<https://www.servicesaustralia.gov.au/individuals>

<https://www.servicesaustralia.gov.au/individuals/topics/payment-and-service-finder/28656>

<https://www.servicesaustralia.gov.au/individuals/services/financial-information-service>

Energy Info Hub

This website, run by not-for-profit energy experts, has everything you need to know to spend less on energy bills at home including well-known tips and surprising suggestions.

<https://energyinfohub.org.au/>

Victorian State Government Concessions (Department of Health & Human Services)

- Utility Relief Grants
- \$250 one-off Power Bonus Grant
- Various other concessions

<https://services.dhhs.vic.gov.au/utility-relief-grant-scheme>

<https://services.dhhs.vic.gov.au/energy>

<https://services.dhhs.vic.gov.au/about-concessions>

Alternatively contact the Victorian Concessions Information Line on 1800 658 521 (free call) or email concessions@dhhs.vic.gov.au

MS

- A combined entity of the ACT, NSW, Victoria and Tasmania providing information, advice, services and support for people living with multiple sclerosis.
- There is a series of webinars related to improving your financial wellbeing.

<https://www.ms.org.au/>

or Phone

MS Connect on 1800 042 138

<https://www.ms.org.au/support-services/education/webinar-library.aspx>

Social Security Rights Victoria

- SSRV is a community legal centre that provides free legal services in relation to Social Security & Centrelink matters to people across Victoria.
- The Disability Support Pension (DSP) Toolkit and DSP Help Online Service can also be found on this website – useful resources to guide you in submitting the appropriate information in a DSP application.

General Advice Line: PH: 03-9481 0355

Monday – Thursday

9.30am – 12.30pm

<https://www.ssrv.org.au/>

General Enquiries: Phone 03 9481 0299

Monday – Thursday

9.00am – 5.00pm

<https://www.ssrv.org.au/>

<https://www.ssrv.org.au/toolkits/>

<https://dsphelp.org.au/>

Rental Issues

- Justice Connect – “Dear Landlord App”
- Tenants Victoria <https://apps.justiceconnect.org.au/dear-landlord/>

<https://tenantsvic.org.au/>

Scams

- What to look out for and how to report a scam.

<https://www.scamwatch.gov.au/report-a-scam>

Emergency Relief Services

The Department of Social Service has a directory of Grant Services which can be searched by postcode.

<https://serviceproviders.dss.gov.au/>

Gilenya to Lemtrada



This article is with thanks to: <https://multiplesclerosisnewstoday.com/>

Previous treatment with oral Gilenya (fingolimod) is associated with a suboptimal response to Lemtrada (alemtuzumab) and an increased risk of secondary autoimmune disorders in multiple sclerosis (MS) patients, a study reports.

However, Lemtrada showed an efficacy in patients switching from various other disease modifying therapies (DMTs) similar to that seen in people naive to such treatment. These findings “can provide guidance for improving MS therapeutic management,” the investigators wrote.

The study, “Impact of previous disease-modifying treatment on effectiveness and safety outcomes, among patients with multiple sclerosis treated with alemtuzumab,” was published in the *Journal of Neurology, Neurosurgery and Psychiatry*.

First-line treatments for relapsing-remitting MS (RRMS) are often lower-risk DMTs like interferon-beta (IFN-beta, examples include Avonex), and Tecfidera (dimethyl fumarate). People generally switch to more highly active therapies, such as Gilenya and Tysabri (natalizumab), if disease activity persists.

Lemtrada was shown in clinical trial to effectively reduce disease activity in treatment-naive patients and in those unresponsive to first-line DMTs. However, data regarding Lemtrada after other DMTs use can be both inconsistent and incomplete, complicating efforts to manage progression.

“Real-world data on specific treatment sequences remains sparse and the optimisation of the escalating therapeutic management remains short of general consensus,” the researchers wrote.

As Lemtrada carries a significant risk of side effects, such as stroke or secondary autoimmune disorders like thyroid disease and autoimmune hepatitis, doctors should be aware of patients groups for whom Lemtrada is not as safe and effective as was shown in clinical trials. Researchers in Germany examined 170 MS patients given Lemtrada in a real-world setting to better understand the potential impact of prior treatments.

They were part of the PROGRAM-MS study (NCT04082260), investigating predictors of Lemtrada responses in people with active disease. Those enrolled were either treatment naive or had failed to respond at least six months of treatment with IFN-beta, Tecfidera, Gilenya, or Tysabri.

All were given at least two Lemtrada infusion courses between February 2014 and April 2018, and were followed for at least one year after the second course.

Of these 170 RRMS patients, 50 had previously received Tysabri, 33 switched from Gilenya, 52 had used IFN-beta or Tecfidera, and 35 were new to treatment. Most who switched did so because of disease activity, although 21 people on Tysabri with stable disease changed due to the risk of progressive multifocal leukoencephalopathy (PML, a severe brain disease).

Overall, 78 patients (45.9%) had at least one relapse during the study period, with those given Lemtrada as a third-line treatment at a significantly higher risk of relapse than those using it as a first- or second-line treatment.

Compared with other DMTs, previous treatment with Gilenya was the strongest predictor of relapse after Lemtrada infusion — these patients were 5.4 times more likely to experience a relapse than other patients. Additional risk factors were relapse rates before initiating Lemtrada and prior treatment with Tysabri. Moreover, the risk of disability worsening after Lemtrada infusion was significantly higher — by 7.7 times — in patients previously treated with Gilenya than in treatment-naive patients.

Gilenya-treated patients also had a higher incidence of spinal relapses compared with naive patients (55% vs, 10%), and a higher risk of developing a secondary autoimmune disease compared with those in other treatment groups.

Over the first two years after starting with Lemtrada, patients’ annualized relapse rate was significantly lower from a pre-Lemtrada period across all groups, including those new to treatment (1.15 vs. 0.33 relapses per year), IFN-beta or Tecfidera-treated patients (1.47 vs. 0.16), stable Tysabri-treated patients (0.45 vs. 0), and active disease Tysabri-treated patients (1.55 vs. 0.38).

Gilenya-treated patients also experienced a smaller but still significant reduction in relapse rates within two years of starting with Lemtrada (1.46 vs. 0.90). “Although the efficacy of [Gilenya] has been proven in various clinical trials ... our data indicate [Gilenya] pre-treatment as a risk factor for suboptimal therapeutic response to [Lemtrada] and for developing secondary autoimmunity,” the researchers wrote.



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