

Issue 54 - August 2017

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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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Mahi tatau ki te whakawhiwhi he hapori rawe

'Hobbsy' – On Parade



Have you ever been to an air show or an Armistice Day commemoration and seen a group of men running around 're-enacting soldiers' and thought what a strange bunch? Well chances are you may have seen Philip Hobbs of Hamilton – and think again – those guys are for real.

Philip has Primary Progressive MS and at the time of the interview was an Area Manager for a farm product company. In his "other life" - Philip is a Staff Sergeant for the 18th Battalion, 4th Brigade 2nd New Zealand Expeditionary Force - a member of the WW2 Historical Re-enactment Society. The Society is the oldest such group (21 years) in the country and is based at Auckland's MOTAT.

Philip first encountered the group in 2008 at the annual Armistice Day commemorations in Cambridge. "I was with one of my Brother-in-laws – he knew I was interested in Military history and suggested I should join them and gave me one of their brochures". "I first

got interested in military history when I was a kid and watched such movies 'Zulu Dawn' (great movie by the way – one of Michael Cain's best) and then I would go and re-enact the whole battle again! My grandmother made me the uniform and grandfather made me the gun. After that I made and collected plastic military models and studied military history. I was hooked!"

From college years Philip started collecting items of uniform and weaponry from his favourite Hamilton store 'Valentines' - leading years later to joining the group in 2010. He was told right from the start that his uniform and equipment needed to be as accurate as it could be to the time period. "We take it very seriously" says Philip "Every item of uniform has to be accurate for the soldier you are representing - we need to respect the uniform in honour of those who actually wore the kit".

Kit and equipment is getting harder to find –as its over 70 years old – so some

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'Hobbsy' – On Parade (continued)

is reproduction and when possible – original. Philip says they are fortunate that on some occasions people will donate items so as to see it go to good homes – "we will treasure family items and give the public a chance to see them". These items range from tents, to uniforms, equipment and even paperwork – all are given a new home.

The Society has four units - 2NZEF 18th & 21st Battalions

- American 82nd Airborne
- German Paratroopers The Fallschirmjager

After a couple of years Philip found himself President of the Society – a position he held for three years and he is now on the Committee. The Society trains once a month and during the summer months has shows that may take the form of battles, static displays and/or blank firing weapon demonstrations. All battle scenarios' are meticulously researched and are performed as close to reality as their location and props will allow. "We don't see ourselves as 'playing at war'- rather as living historians – keeping the memory alive and educating the public" says Philip. "It is really important to us that we respect the memory of those who wore the kit and those who still do – and I think we do. We even have veterans who will come up to us and thank us for our efforts'.

As to how does Philip get on with his MS. "Well when I put on my uniform I like to think I haven't got MS – the walking stick was quite the norm in the 1940's!" But of course it hampers my movement and I must admit I spend my "battle time" being rescued and carried by stretcher to a waiting ambulance or dying heroically fighting the enemy from the front of a jeep!" "But usually most of the time I stay with our display and take questions and educate the public – I particularly like encouraging children to ask questions at home about their own family's military history. I really enjoy this aspect – lest we forget".

As for Philip's MS he felt his first symptoms in 2000 after running a marathon when he started dragging his right leg. He didn't think too much about it at the time but the condition kept persisting to the point he couldn't run at all and was actually falling over. After a lot of tests, various treatments and a lot of frustration in 2005 he underwent keyhole surgery to correct some hip damage. At the time he was told that this would help him run again - but it didn't and he couldn't! In 2006 he had a diagnosis that he had MS - given some steroids and sent on his way.... "A friend of my father-in-laws who had MS gave me a book and dvd of Dr. Jelinek's -Overcoming MS. So I have self-managed since with diet and exercise" says Philip. His condition got gradually worse and then in 2011 he had a second diagnosis of MS by Chris Lynch (Neurologist). He has managed to battle along since, working in sales related roles in the farming industry. "Funny thing is", Philip reckons "I think having MS, and being honest about it, has helped me get a foot in the door with some of the farmers. They are very up-front and don't put up with any bulls**t. When they ask me what's up with my leg I tell them about MS and it seems to break down a hidden barrier - I have shared something very personal and so I get credibility straight away which gives me a chance to start chatting with them".

Philip is looking forward to a couple of upcoming events for the WW2 Historical Re-enactment society. "The 75th anniversary of the raid on 'Barce – an Italian air field in Libya by the LRDG, (probably their most successful raid), is coming up in September in Paeroa and November in Cambridge. We will be putting up a display of the Long Range Desert Group (which involved a high proportion of NZ Troops) and was the fore-runner to what we now call the SAS.

Shoulders back, head up Hobbsy - 'on the double'!

Ian Maxwell









SmartHealth – What is it?

SmartHealth is a free online healthcare service delivered by HealthTap.

You can talk to an online doctor out of hours and at weekends by video, voice or text chat, and access a knowledge base of doctor approved health information on topics, conditions, treatments and research.

If appropriate for your condition, you can also schedule online appointments with hospital specialists from wherever you are. It means less travel and time required for hospital appointments.

If you are covered by Waikato District Health Board services wherever you are in NZ or abroad, you can sign up to SmartHealth and then download the free HealthTap app.

Why should I use SmartHealth?

- It's a Doctor in your pocket save time and get answers when you need them wherever you are:
 - 6pm 11pm Monday Friday 8am to 8 pm Saturday, Sunday and Public Holidays.
- It's loaded with Doctor approved information you can trust.
 - Search the knowledge base, or have your question answered directly by a doctor already in the system.
- Organise your healthcare: Secure, private and convenient, HealthTap lets you link everyone in your healthcare team together. You can access your HealthTap clinical record and consultation notes any time.

Sign up at www.smarthealth.org.nz

The Alinker

What is the Alinker?

The Alinker is a non-motorised three-wheeled walking bike without pedals that's designed for people who want to stay active regardless of their mobility challenges.

- · Allows for low-impact, strength-building physical exercise
- Allows for travel across longer distances with less fatigue
- Lightweight, foldable frame for easy transport.

This cool new bike is challenging assumptions about people with disabilities and is striving to build a more inclusive community.

- User sits upright, at eye-level with their companions
- Feet remain on the ground keeping users stable and safe
- Allows for independent operation without assistance
- Allows users to feel equal and included

For more information on the Alinker visit www.thealinker.com. This is available to purchase from Life Unlimited, visit www.lifeunlimitedstore.co.nz or ring 0800 008 011.



Minister for Disability Issues Media Statement

New services to support disabled people in work

New services to support disabled people in work

Disability Issues Minister Nicky Wagner announced two new support services to help disabled people and people with health conditions stay in work.



"Disabled people and people with health conditions make great employees and most need little to no support, but sometimes the people employing them do", Ms Wagner says.

"That's why we've set up the Employer Advice Line – a free phone based service offering advice to employers about how to support new or existing disabled employees".

Callers get information and advice specific to their situation, including local support services and organisations. Work and Income is also providing phone based support to its recently employed clients.

"The Government is committed to improving employment outcomes for disabled people and people with health conditions".

The Employer Advice Line is operated by Homecare Medical, which also runs Healthline, Quitline, Alcohol Drug Line and Depression Helpline. It is available Monday – Friday 8.30am – 5.00pm on 0800 805 405.

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Study Discovers New Gene Responsible for **Huntington's Disease Progression**

This research has exciting findings & reinforces the importance for people to participate in large HD studies such as TRACT-HD and EHDN's REGSTRY! See the study's summary below this article.

http://www.raredr.com/news/new-gene-responsiblefor-hd-progression

Mathew Shanley, Rare Disease News - Published Online: Thursday, Jul 06, 2017

Per a British study published in Lancet Neurology, mutations of the MSH3 gene may be associated with Huntington's disease (HD) progression. Conducted by researchers from University of College London (UCL) and Cardiff University in Wales, the study, "Identification of genetic variants associated with Huntington's disease progression: a genome-wide association study" found that the gene could become a biomarker for HD and its identity could lead to future treatment options for this fatal, neurological disease.

HD is due to a mutation on the Huntingin gene and almost always results in the progressive loss of both mental and motor control. Symptoms most frequently show when the patient is between the ages of 30 and 50 years, and progress over a 10 - 25 year period until death. The new study indicates that the Huntingtin gene is not the only gene involved in disease progression.

"We've identified a gene that could be a target for treating Huntington's disease. While there's currently no cure for the disease, we're hopeful that our finding could be a step towards life-extending treatments," said lead author Dr. Davina Hensman Moss of the UCL Huntington's Disease Centre and UCL Institute of Neurology. "The gene variant we pinpointed is a common variant that doesn't cause problems in people without HD, so hopefully it could be targeted for HD treatments without causing other problems," Moss continued.

Information captured in both the TRACK-HD study (n=216) and the much larger European Huntington's Disease Network REGISTRY study (n=1773) were compared, as researchers evaluated the cognitive and movement symptoms in both. Symptoms and the disease's progression with the genetic mutations in the combined 1,991 patients were also compared.

It was discovered that mutations in the MSH3 gene, as well as 2 other genes - DHFR, and MTRNR2L2 - were associated with disease progression in both studies. MSH3, a DNA repair gene, has already previously been linked to changes in size of the HD mutation, and it was identified in the study that a variation in it encodes an amino acid change.

"This is an example of reverse translation: these novel findings we observed in people with HD support many years of basic laboratory work in cells and mice," said the study's co-senior researcher Dr. Sarah Tabrizi of UCL. "Now that we know that MSH3 is critical in the progression of HD in patients, we can focus our attention on it and how this finding may be harnessed to develop new therapies that slow disease progression."

"The strength of our finding implies that the variant we identified has a very large effect on HD, or that the new progression measure we developed is a much better measure of the relevant aspects of the disease, or most likely, both," said the study's other co-senior researcher, Cardiff University professor Dr. Lesley Jones.

Reference: Hensman Moss DJ, Pardinas AF, Langbehn D, et al. Identification of genetic variants associated with Huntington's disease progression: a genome-wide association study. Lancet Neurol. 2017; DOI: 10.1016/ \$1474-4422(17)30161-8

Identification of genetic variants associated with Huntington's disease progression: a genome-wide association study

http://www.thelancet.com/journals/laneur/article/ PIIS1474-4422(17)30161-8/fulltext

Lancet Neurol. 2017; Published: 19 June 2017 DOI: http://dx.doi.org/10.1016/S1474-4422(17)30161-8

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Langbehn, PhD, Kitty Lo, PhD, Prof Blair R Leavitt, MD, Prof Raymund Roos, MD, Prof Alexandra Durr, MD, Prof Simon Mead, PhD. TRACK-HD investigators†, the

REGISTRY investigators† Prof Peter Holmans, PhD, Prof Lesley Jones, PhD§, Email the author Prof Lesley Jones, Prof Sarah J Tabrizi, PhD

Summary

Background: Huntington's disease is caused by a CAG repeat expansion in the huntingtin gene, HTT. Age at onset has been used as a quantitative phenotype in genetic analysis looking for Huntington's disease modifiers, but is hard to define and not always available. Therefore, we aimed to generate a novel measure of disease progression and to identify genetic markers associated with this progression measure.

Methods: We generated a progression score on the basis of principal component analysis of prospectively acquired longitudinal changes in motor, cognitive, and imaging measures in the 218 indivduals in the TRACK-HD cohort of Huntington's disease gene mutation carriers (data collected 2008-11). We generated a parallel progression score using data from 1773 previously genotyped participants from the European Huntington's Disease Network REGISTRY study of Huntington's disease mutation carriers (data collected 2003–13). We did a genome-wide association analyses in terms of progression for 216 TRACK-HD participants







and 1773 REGISTRY participants, then a meta-analysis of these results was undertaken.

Findings: Longitudinal motor, cognitive, and imaging scores were correlated with each other in TRACK-HD participants, justifying use of a single, cross-domain measure of disease progression in both studies. The TRACK-HD and REGISTRY progression measures were correlated with each other (r=0.674), and with age at onset (TRACK-HD, r=0·315; REGISTRY, r=0·234). The meta-analysis of progression in TRACK-HD and REGISTRY gave a genome-wide significant signal ($p=1.12?\times?10?10$) on chromosome 5 spanning three genes: MSH3, DHFR, and MTRNR2L2. The genes in this locus were associated with progression in TRACK-HD (MSH3 p=2.94?×?10?8 DHFR p=8.37?×?10?7 MTRNR2L2 p=2.15?×?10?9) and to a lesser extent in REGISTRY (MSH3 p=9.36?×?10?4 DHFR p=8.45?×?10?4 MTRNR2L2 p=1.20?×?10?3). The lead single nucleotide polymorphism (SNP) in TRACK-HD (rs557874766) was genome-wide significant in the meta-analysis (p=1.58?×?10?8), and encodes an aminoacid change (Pro67Ala) in MSH3.

In TRACK-HD, each copy of the minor allele at this SNP was associated with a 0-4 units per year (95% CI

0.16-0.66) reduction in the rate of change of the Unified Huntington's Disease Rating Scale (UHDRS) Total Motor Score, and a reduction of 0.12 units per year (95% CI 0.06-0.18) in the rate of change of UHDRS Total Functional Capacity score.

These associations remained significant after adjusting for age of onset.

Interpretation; The multidomain progression measure in TRACK-HD was associated with a functional variant that was genome-wide significant in our meta-analysis. The association in only 216 participants implies that the progression measure is a sensitive reflection of disease burden, that the effect size at this locus is large, or both. Knockout of Msh3 reduces somatic expansion in Huntington's disease mouse models, suggesting this mechanism as an area for future therapeutic investigation.

Funding: The European Commission FP7 NeurOmics project; CHDI Foundation; the Medical Research Council UK; the Brain Research Trust; and the Guarantors of Brain.

Clinical Exercise Physiology

Bonjour, my name is Carrie I am completing accreditation in Clinical Exercise Physiology as an intern and the 2 x Gold level award Biokinetic Clinic at the Wintec Rotokauri campus.

I apply an Exercise is Medicine philosophy to scientific protocols relative to specific chronic conditions ie. cardiac, respiratory and neurological. I aim to preserve and improve functional skills like balance, coordination, mobility and aerobic tolerance.

My service is free for 12 weeks and I would love to meet you.

Please contact Carrie Aspin, PG Clinical Exercise Physiology student on 027 463 0089 or aspincarrie@gmail.com

Achilles International

Achilles International is an organization which enables people with all types of disabilities to participate in main stream athletics, promotes personal achievements, lowers barriers and enhances self-esteem.

Achilles International was formed in New York in1983 by Dick Traum who became the first amputee to complete the New York Marathon in 1977. Athletics coach Peter Loft assisted Traum with his fitness and accompanied him on the run.

In 1993, now based in Whangarei, Peter returned to New York with John Riley (an above knee amputee) and completed the marathon again. On their return from New York the pair along with other supporters set up the Achilles Track Club New Zealand based in Auckland.

Peter moved to Hamilton in November and set up a chapter of Achilles here (there are also chapters in

Rotorua, Wellington and Christchurch). Currently Peter has 20 members and their guides who attend training every Wednesday. Peter says everyone is treated exactly the same – no matter what their disability and that the athletes guides are the backbone of the organization.

Achilles support people to participate in both local mainstream events and the high profile New York marathon. Peters aim is to get to the New York marathon again – Achilles members get free entry. Peter has worked with some MS clients including Auckland woman Nic Miller-Clendon who completed the race twice. Peter himself has attended the marathon 20 times and ran it 16 times.

If you are interested in finding out more about Achilles you can contact Peter at peterloft51@gmail.com.

Ian Maxwell

ms.

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of Koru please notify Tracey by emailing tracey@mswaikato.org.nz

Upcoming Events

MS Awareness Week

MS Awareness week runs from Monday 28th August to Sunday 3rd September. Please can you help? Awareness week is an opportunity to raise both awareness of Multiple Sclerosis and to fundraise.

We need volunteers to help on our stalls on Wednesday 30th, Thursday 31st or Friday 1st September – do you have a couple of hours you could spare? Perhaps you may have friends or family who would assist with a stall too.

There are many different ways to fundraise and you may like to organise something yourself; perhaps you could sell cup cakes, invite people to create a line of coins, encourage colleagues to take part in a loud tie day or you may have a great idea of your own.

If you are able to help in any way please phone Janet on 07 834 4740 or email janet@mswaikato.org.nz

Mastering Maungataurtari

As many of you can attest to, living with Multiple Sclerosis can be a challenge but Sue Dela Rue has set herself another challenge - to walk Maungatautari Mountain. This is not only a personal challenge for Sue but she is also doing this to raise awareness of MS and as a fundraiser for both MS Waikato and the Maungatautari Ecological Island Trust.

The walk is taking place on Sunday 24th September, you can support Sue through a Give a Little page: https://givealittle.co.nz/fundraiser/masteringmountains or if you would like to join Sue for the day email liz@mswaikato.org.nz, staff will be walking too. To read Sue's blog go to http://www.masteringmountains.org/update-from-sue/

Kawhia Cruise

Join us for Adam Muirs Annual Fundraiser on Sunday 12th November; the cruise is now in its 5th year.

Starting with breakfast at 8.00am at the Classics Museums Jukebox Diner,

9.30 am leave the museum for Pirongia

10.00 am start at Pirongia for those wishing to join the rally

11.30 am arrive at Oparau Roadhouse for lunch

This will be followed by an auction and cruise onto Kawhia. 'Shotgun', the classic rock band will perform at Kawhia from 1.30pm.

To take part 'put a note in the bucket'! All funds raised to be donated to MS Waikato

For more information email Adam - info@kawhiacruise.com

Totara Springs

We hope to run another MS camp at Totara Springs on 16-18th March 2018.

Please keep the date free, further information and confirmation will be emailed out as soon as this is available. To register your interest for this please email Liz - liz@mswaikato.org.nz

Remember Nikki Ladd?

Last year we met Nikki as she walked the Te Araroa trail to raise money into research for MS. Travelling over 2800km Nikki completed her amazing journey in 129 days. Having broken some bones in her foot earlier in the year Nikki found herself having to take to a push bike part way through the journey, none the less she didn't allow this to slow her down. Nikki raised over \$19.500.

NOTICE BOARD

Facebook

MS Waikato now has a Facebook page; do please follow us on Facebook.

Search for us as MS Waikato; alternatively visit our website www.mswaikato.org.nz and follow the link.

LiveWiseMS

Live Wise MS is a new resource for those affected by Multiple Sclerosis.

'LiveWiseMS is not only sourced by trusted medical content but it is reviewed and approved by the International Organization of MS Nurses (IOMSN), a well-respected organization of nurses who focus solely on the care of those affected by multiple sclerosis.'

To access this go to: www.livewisems.org

Subscriptions

Please note 2017 subscriptions are now due.
The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received.
Thank you for your support.

The Entertainment Book

Entertainment books are still available for purchase.

At \$65 they are available in hard copy or digital format and you will receive thousands of dollars worth of vouchers in our region. Books are also available for other regions. These are sold as a fundraiser.

A sample book is available in the office to view.

To order online go to www.entbook.co.nz/1b54128 or call into the office to purchase a book. Books purchased through this link can be mailed to you for \$8 if required.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz

HDY0

Huntington's Disease Youth Organisation are holding a HDYO Australian/New Zealand Camp on 12 - 15 January 2018 on the Sunshine Coast.

The camp is for families affected by Huntington's Disease and is aimed at 15 – 25 year olds but there is a little flexibility.

The costs for accommodation and travel are covered by HDYO.

To apply go to: https://en.hdyo.org/eve/events/549

MS Awareness Week

MS Awareness week runs from

Monday 28th August to Sunday 3rd September.

Please can you help?

More information is detailed in the events updates. If you are able to assist in any way please phone Janet on 834 4740 or email janet@mswaikato.org.nz.

Payments

If you wish to make any payments directly to the Trust bank account this is 02 0316 0488196 000 Please remember to include your name and what the payment is for eg Subs.

Donations and Bequests

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Thanks to our Sponsors and Supporters























WDFF Karamu Trust • Waipa District Council • COGS - Hamilton City, Hauraki, South Waikato & Waikato West • DV Bryant • Anytime Fitness Tristram St • The Fine Homes Tour • Lochiel Golf Club • The Sutherland Self Help Trust • The Gallagher Charitable Trust • MediSun Ltd Waikato Lyceum Charitable Trust • Trillian Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Glenice & John Gallagher Foundation

MSWT EVENTS CALENDAR



SEPTEMBER 2017

SUN	MON		TUE		WED		THU	FRI	SAT
					IV	IS AWARE	NESS WEEK	1	2
3	4	MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5	MS Support Group Dawn Til Dusk Cafe Te Awamutu 10am	6	MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	7	8	9
10	11	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	12		13	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	15	16
17	18	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	19		20	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	MS Support Group Mometewa Te Aroha 10am	22	23
24	25	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	26		27	MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28 MS Support Group Summerset Down the Lane, Dixon Road 10.30am	29	30

OCTOBER 2017

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NOVEMBER 2017

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					1	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	2		3		4	
5	6	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	7	MS Support Group Dawn Til Dusk Cafe Te Awamutu 10am	8	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	9 1	ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	10		11	
Kawhia Cruise Classics Museum Jukebox Diner 8.00am	13	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	14		15	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	16	MS Support Group Mometewa Matamata 10am	17		18	
19	20	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	21		22	MS Exercise Class 10.30am—11.30am Anytime Fitness 56 Tristram St Hamilton	23 Dow	MS Support Group Summerset In the Lane, Dixon Road 10.30am	24		25	
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