

Warrington Branch

MIScellany

September 2015

October Social

Don't forget Sharon & Jenny the neuro physiotherapists will be at St Joseph's on October 13 for a question & answer session and if time allows a demonstration on the way they approach treatment of people with MS. Don't miss this.

Christmas Party

The Christmas party will be on Saturday 5th December at Statham Lodge 12:30 PM for 1 PM start. We have been guaranteed that we will have roundtables and either the room divider or sole use of the room. This cannot be changed 3 days before the event as happened last year. The menu and reply slip are included with this newsletter. The food is always good and we hope to see as many of you there as possible.



Words from the Editor

First of all apologies to all members that I haven't been in the loop over the last few months. I have been going through a rather exciting time in my life as Jennifer and I have moved into our first property together and can proudly say I couldn't be happier.

As mentioned I haven't been in the loop lately regarding the Society so I am unable to update members on many of the happenings at the moment, however there has been a change to the best way to contact me with any information for the newsletter. The email to send any details through is jordan0489@gmail.com

Members may not be aware that I have transferred back to my old position as an office manager at my old job in Birchwood. The job entails IT recycling so no doubt if any members are looking for computer equipment and they don't want to pay the a small fortune, let me know and I will see what I can do for you. I am also aware of the MS society's used toners scheme which I am looking into at the moment on behalf of CRT to help look at raising money through recycling.

It has been a quite incredible few months after deciding to move home for the first time with Jennifer and take residence in Chapel-ford Village. It is nice and quiet for us both and a pretty easy commute for us both to our places of work so we are both very happy. This was followed by amazing news that my mum is now eligible for a gastric pacemaker which gives her the chance to eat for the first time in over five years. Its been a long drawn out process but we are finally starting to make headway and she is currently awaiting pre-op with a date for surgery.

In a few short weeks I will be heading to Barcelona for a weekend which we are both very much looking forward, then the countdown to Christmas really kicks in! The first in a new home, it promises to be exciting if somewhat nerve-racking at the same time as I take my first attempt at cooking Beef for dinner! (Jen's never been overly keen on the traditional Christmas fayre)

One final note (Non MS Society related) my mum is raising money for Macmillan cancer nurses on September 19th, if you would like details of the location and how to get involved, please send me a very quick email and I can send over details.

Jordan Knight

Unwanted Clothes and Shoes Bags and Belts

As a branch we are now recycling and can turn your unwanted items into branch funds

Must be clean and dry

Contact Peter Travers tel. 492970



Monday
Pub Lunch Club
1st Monday
of the month

Currently using
Chapelford Farm
Warrington

Alternative
suggestions welcome

Contact Peter Travers
(01925) 492970



Our Congratulations to:-

Rita DALY	24-Sep
Glenis ENRIGHT	25-Sep
Les BAYLISS	29-Sep
Jane AVERY	01-Oct
Stephen ROBINSON	16-Oct
Janet BRAMALL	25-Oct
Philip JONES	26-Oct
John McQUILLAN	28-Oct
Lee GORMAN	23-Nov

100+Club



There are 117 members if you're not one of them please consider joining contact Chris Janovitz on 723564. Remember the more people join the higher the prizes go don't delay.

14th July 2015
Members 119

11th August 2015
Members 117

Prize	Num	Name
1st	089	Sheila Wareham
2nd	046	John Paice
3rd	045	Julie Richards
4th	014	John McQuillan
	087	John Curley
	001	John Burke
	037	B Taylor
	109	Sue Burns

Prize	Name
1st	034 K Mitchell
2nd	020 Mary Burke
3rd	086 Olive Curly
4th	117 Stephen McNamara
	063 F Dooley
	110 Roger Williams
	009 Charles Dooley
	055 Chris Janovitz

The amounts were £119.00, £66.00, £40.00 and 5 at £10 respectively

The amounts were £117.00, £65.00, £39.00 and 5 at £10 respectively

6 Mobility Scooters	Birchwood Shopping Centre	Parcel delivery		Service: Accounts
	Telephone 01925 822411 To reserve			
Available		Dave Hinde Travel Services	D.H.T.S. Disabled Travel Service Mobile 07887 615040	

Listening Ear - Margaret Hughes -(01925) 723917

Fundraising

Dorothy and Elaine went to support Chris Ball on Friday 14th of August in the afternoon. He was doing a sponsored run 73 x 1 mile laps round Orford Park in memory of his father who would have been 73 on the day.

Unfortunately his father, who was a member of Warrington branch, passed away in December last year and Chris wanted to mark the occasion. He started at 4.30 am (yes, morning) in the pouring rain and only finished at 8.30 pm.

Both Dorothy and I did a lap with him and during the day he was interviewed on Wire FM and Warrington Guardian came along and took a photo and details of the run to feature in their newspaper. The people in the cafeteria at Jubilee Hub donated £100 and Chris is hopeful of getting in a good sum for our branch.



Thank you Chris and all your family who were also all there to support you. Warrington branch committee and members appreciate your efforts in this very gruelling run under such awful weather conditions.

Over £1100 has been collected so far the final figure will be included in the next newsletter.

 <p>MS Nurse Clinic Carolyn Cairns 0151 529 5645 Woolston Clinic 2nd Monday of the month 2 PM</p>	<p>Support Your Branch</p>  <p>Attend Socials Outings</p> <p>Join the hundred+club</p>
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— Vitamin D link to MS Becoming Clearer —

New research published in the journal PLOS (Public Library of Science) Medicine strengthens the evidence for vitamin D's role in MS risk.

The potential link between vitamin D and the risk of developing MS has been an active area of research for a number of years now. Research published this week has brought us an exciting step closer to understanding the biological nature of the connection between MS and Vitamin D. A new study, led by researchers at McGill University, Canada, suggests a causal link for the first time. It suggests that people who are genetically predisposed to having low vitamin D levels are more likely to develop MS.

Large-scale study: Researchers used data from two large genetic studies to draw these conclusions. The first was a European study of 34,000 people's genes associated with vitamin D deficiency (the SUNLIGHT study). The second was the largest international genetic study of MS (the International Multiple Sclerosis Genetics Consortium ImmunoChip study), involving 14,498 people with MS and 24,091 controls.

Researchers found four genetic variants that are closely associated with vitamin D levels, and analysed whether or not these were more common in people with MS. The results showed that people who carried these variants (and so were genetically prone to having lower vitamin D levels) were at a higher risk of developing MS.

What this means for people with MS These findings bring us closer to understanding how important vitamin D is in MS. But they don't tell us whether taking vitamin D supplements could reduce your chance of developing MS, nor whether vitamin D could affect the course of MS after its onset.

If have any concerns about getting sufficient vitamin D from sunlight or your diet, you should discuss them with your health care professional.

Research priority: At the MS Society, investigating whether taking vitamin D supplements could bring benefits to people with MS is

one of our top 10 research priorities. Although this study doesn't go as far as investigating how vitamin D could modulate MS after onset, it does demonstrate significant progress in the area.

An exciting step forwards: Dr Susan Kohlhaas, Head of Biomedical Research at the MS Society says: "More than 100,000 people are affected by multiple sclerosis in the UK so the potential link between vitamin D and the risk of developing MS is an incredibly crucial area of research. There are many unanswered questions around what causes MS so this large scale study is an exciting step towards understanding more about the complex nature of the genetic and environmental factors that contribute to it."

"There are government guidelines around how much vitamin D people should take, and taking too much can lead to side effects so we'd encourage people to talk to their health professional if they're thinking of doing this. We'd also welcome more research into this area, as we know it's really important to people living with MS."

Published date: 25 Aug 2015

The logo for Creative Remedies features the text "Creative Remedies" in a white, sans-serif font, centered within a solid teal rectangular background. The logo is flanked by two horizontal lines on either side.

Creative Remedies is an Art on Prescription scheme which aims to help improve the health and wellbeing of adults living in the Warrington area. We hold weekly groups in community venues and provide all equipment needed, the groups are led by friendly experienced tutors.

We provide lots of varied groups some of which include: Performing Arts, Golf, Tai Chi, Art, Photography, a social group called the 'Breeze in' group and a Read 2 Relax session. Most groups are held in the Pyramid centre with the exception of the 'Breeze in' group and the golf.

If you would like a chat about any of our groups, or for group times and information, please call 01925 573489 and ask for a member of the Creative Remedies staff. Or email Sue Hogan on shogan1@warrington.gov.uk

MD1003 also known as Biotin

MD1003 is an oral medication that is in development for progressive MS and is currently in phase 3 clinical trials for progressive MS and optic neuritis.

Current phase of trial: phase 3 for progressive MS and optic neuritis (inflammation of the optic nerve)

How does MD1003 work? MD1003 is a highly concentrated form of biotin, a vitamin(B7) that activates some enzymes involved in cell growth and myelin production

How is MD1003 taken? It is an oral capsule.

Latest research In April 2015, results from a phase 3 clinical trial testing the effectiveness of MD1003 as a treatment for progressive MS were announced at a conference by MedDay (the biotechnology company behind MD1003).

The trial involved 144 participants with primary or secondary progressive MS split into two groups, receiving either:

- 300 mg of MD1003 daily for 24 months
- a placebo for 12 months followed by 300 mg of MD1003 daily for 12 months

Researchers were measuring whether participants had any improvement in disability at 9 months of treatment that was still apparent at 12 months. Approximately 13 per cent of the treatment group compared to none of the placebo group met this criteria demonstrating some improvement in the treatment group. The announcement was made part way through the trial, with full completion estimated to be early 2016.

Optic neuritis MedDay is also currently carrying out a phase 3 clinical trial testing the effectiveness of MD1003 as a treatment for optic neuritis. 105 participants with MS who experience optic neuritis have been split into two groups, receiving either:

- 300 mg of MD1003 daily for 12 mths
- a placebo for 12 months then 300 mg of MD1003 for 6 mths

The trial is due for completion mid-2015, and aims to test the effect of MD1003 on the clearness of vision and the thickness of the retina (the light sensitive nerve fibre layer at the back of the eye).

Earlier results A small pilot study involving 23 participants with primary or secondary progressive MS demonstrated that high doses of MD1003 may lead to improvements in disability. This was a non-blinded study (doctors and participants were aware they were taking MD1003), where participants were given 100-300 mg of MD1003 per day for 2 to 36 months. 21 out of the 23 taking part showed evidence of some kind of improvement, including improved vision, cognition or walking.

What are the side effects of MD1003? No significant side effects were reported during the small pilot study.

How does MD1003 compare with current therapies? MD1003 has not yet been compared with current therapies in clinical trials.

When is MD1003 likely to become available? If this phase 3 trial is successful, a larger phase 3 trial may be required to confirm its effectiveness in progressive MS. Research is still at an early stage, and it will be a few years before we know if this is an effective treatment for people with MS.

Unlike the MS society I'm not prepared to wait another few years to see whether it works or doesn't pharmaceutical grade biotin is available from the USA and Canada as a bulk powder a year's supply costs around £140 plus a scale able to weigh .001 of a gram. The dose is 300 mg a day and I have been taking this amount since mid June mixed with water and drunk. There are no dramatic changes in my condition but it took me 26 years to get where I am now so I am prepared to give biotin at least a year to see whether it makes a difference.

It is only vitamin B7 and although the dose is massive compared to the recommended daily allowance I have had no side-effects. (300 mg is about the size of a paracetamol tablet) There is a Facebook group currently I think at about 1600 members worldwide most of whom are trying this treatment. Anybody wanting details please email me Chris@janovitz.me.uk.

Truffles Tales

Well here I am on my own Bessy and Dougie are away on respite while Mary and John have a holiday. A lot has been happening in my life, I've had my first haircut what a shock that was. I've been to the grooming parlour several times since taking up residence in Penketh and it's always been a pleasant experience eyebrows and beard trimmed a nice warm shower and a blowdry and I did smell sweet. However on this occasion I've been scalped all over and what a shock that was to my system. I've included a photograph which really doesn't show the full extent of how naked I feel.

I've been to the vet a few times as well problems with my ears lots of dogs like me have this, the vet said I might be allergic to something well let me tell you I am and it's her. In the conversation I heard that when I'm seen to next month they'll give them a good clean out whilst I'm under the anaesthetic. What's this all about and Bessy is not here for me to ask her.



Well I hope I'm still here next time I believe that that will be the Christmas issue I was too young last year to know what it's all about but I do remember presents and plenty to eat. See you all soon. Truffle

Forthcoming Events	
13th October	Social St Josephs Club Penketh Neuro Physio
10th November	Social St Josephs Club Penketh Hotpot
28th November	Pantomime Everyman
5th December	Statham Lodge Christmas party 12:30 PM
Requests for transport - Jeff Richards 07738609018	

Membership News

Unfortunately since last newsletter there has been 4 deaths Miss Valerie Stock died on 29 May 2015 and her funeral on 10 June was attended by Dorothy Lewis, Peter Travers and Esther Thomas. Margaret Bennett died on 9 July and unfortunately we were not made aware of this until after the funeral. Mary Ferguson died on 14th of July 2015 and her funeral on 23rd of July was attended by Dorothy Lewis. Dilys Shenton died on 31st of July 2015 and her funeral on 14th of August was attended by Dorothy Lewis and Jim O'Connor. Our thoughts are with family and friends at this time.

We also have one new member.

With this newsletter is the booking slip for our Christmas party which again will be at Statham Lodge Lymm. We have been guaranteed roundtables so a suitable table plan will be provided. To secure the roundtables we have had to move to a Saturday and the chosen date is 5th of December 12:30 PM for 1 PM start. An addressed envelope has been provided for return of the booking slip but it will require stamp, the menu has also been included but there is no need for you to select your meals now the choice will be made at the table. We look forward to seeing as many of our members and friends as possible and I hope the change to a Saturday will not be an inconvenience.

Our secretary Mrs Elaine Magill has for personal reasons had to resign, this important role will have to be filled so if any of our members or friends would like to consider this please get in touch with any committee member.

MS Helpline Freephone 0808 800 8000
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<http://warringtonms.org.uk>
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Executive Committee September 2015

Branch Officers

Chair	Mr Paul Harrison.....	01606 892151
Treasurer	Mr John Burke	824041
Secretary	Vacant	

Committee Members

Lead Support	Mrs Dorothy Lewis	268820
Fundraising	Mrs Julie Richards.....	573980
Joint Equipment/ Transport	Mr Jim O'Connor.....	451472
Web/DTP	Mr Jeff Richards.....	07738609018
Newsletter	Mr Chris Janovitz.....	723564
Support	Jordan Knight	
Activities	Mrs Rita Harrison.....	01606 892151
Social	Mrs Margaret Wilmot.....	755017
Subscriptions	Mrs Louise Jones.....	265239
Everybody's Help	Mr Peter Travers.....	492970
Everybody's Help	Mrs Mary Burke.....	824041
Everybody's Help	Mr Charles Dooley.....	860112
Everybody's Help	Ms Anita Dubique-Ashton...	828282

This newsletter is published by The Warrington and District branch of the Multiple Sclerosis Society. We give regular updates about MS and what is happening locally in the MS community.

Editor: Jordan Knight
Layout & printing Chris Janovitz

All views expressed in the publication are individual and not necessarily the view or policy of the charity and its supporters.

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