

# Warrington Branch

## MIScellany

February 2017

Here we are in March 2017 six weeks from Easter and I've not got over Christmas and New Year yet, so apologies for the newsletter lateness. There just doesn't seem enough hours in the day to get done what needs doing but hours have to be found.

The first social of the year took place on 14 February in a different room at St Josephs club. The room smaller than the hall we were used to but more comfortable with a friendlier feel to it. Unfortunately probably due to the inclement weather on the night it was not very well attended. Please think about attending future socials especially when the weather gets warmer. It's no fun turning out when it's cold and wet.

I know this is a first contact since last October I hadn't realised it was so long ago so happy New Year to all. The Everyman pantomime and Christmas dinner in December went well although the numbers were down at the dinner. Do we need to look somewhere else for this function? All suggestions welcome.

There are plenty of changes taking place within the structure of the MS Society, we have even got a new logo. The changes I don't think will make a great deal of difference to individual members I suppose it's all to do with making the society fit for the 21st-century. There will be no need to hold an annual meeting were committee members are elected.

## — Integrated Neurological Nurse Specialist —

The integrated neurology nurses (INNS) will work to ensure all parts of the health and social care are talking to each other to ensure you receive the care you need.

The clinics will be in local community settings to see patients with long-term neurological conditions mainly Parkinson's, Motor Neuron Disease, epilepsy and Multiple Sclerosis.

They also provide home visits for patients who are physically unable to attend clinic appointments.

They will also carry out reviews to enable them to see patients who previously may have missed out on or would not have had access to specialist services.

The INNS can prescribe medications; ensure your services are communicating in the best interests of the patient as one of the focuses of the role to help prevent hospital admission.

They will provide educational support for community therapists and health professionals to enable them to support patients with neurological long-term conditions.

It is planned that the INNS will develop meetings where a range of services can come together to review and further develop care planning around individual people with neuro conditions

The nurses will support the nurse advice line so patients can discuss and have their needs met via phone conversations.

The nurses will review someone's care if they are admitted to hospital.

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Listening Ear - Margret Hughes - 01925 723917  
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**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:-*

Paul GRAYSON	04-Mar
Jayne DOLPHIN	09-Mar
Adelaide HOUGH	25-Mar
Sandra CURLEY	26-Mar
Margaret PRICE	18-Apr
Patricia DAWBARN	19-Apr
John PAICE	26-Apr
Maureen MORGAN	20-May
James WILMOT	27-May
Julie HOLIDAY-PLATT	31-May

**MS Helpline Freephone**  
**0808 800 8000**

## **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**

## 100+Club



There are 114 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.

21 January 2017  
Members 114

Prize	Num	Name
1st	074	Colin Donaldson
2nd	126	Chris Jervis
3rd	003	J Wolowicz
4th	073	Angela Pettigrew
	019	Liz Spensley
	091	Mary Williamson
	084	Margo Davies
	097	Mary Barbour

The amounts were £116.00, £62.00, £37.00 and 5 at £10 respectively

14 February 2017  
Members 114

Prize	Num	Name
1st	055	Chris Janovitz
2nd	057	K Maddocks
3rd	102	J Moston
4th	029	Jill Sherratt
	024	Dorothy Lewis
	013	S Rainford
	125	S Wilkinson
	107	Esther Thomas

The amounts were £116.00, £62.00, £37.00 and 5 at £10 respectively.

## Membership News

Unfortunately since the last newsletter there have been 3 deaths amongst our members Stephen J Berry died on 20 October 2016, David Charnley died on 13th January 2017 and Glenis Enright died on 1st February 2017. Our thoughts are with their friends at this time.

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<http://warringtonms.org.uk>  
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## Donations & Fundraising

28<sup>th</sup> of November 2016 - 26<sup>th</sup> of February 2017

Anonymous donation	£50
Peter Travers in lieu of presents	£155
Inner Wheel Club	£50
Anita Dubique-Ashton	£30
Social raffles	£140
Cash4Clothes	£58
Hundred +club	£184
Ann Patterson	£50
Adelaide Hough bridge parties	£902
In lieu of Christmas cards	£65
Donations with subs	£35
Stockton Heath Lions	£350
Hundred +club	£310
In memoriam	
David Charnley	£325 (Research)
Nina Cruickshank	£15

**P**ictured right are two members of Stockton Heath Lions Club International presenting a cheque for £350 to Julie Richards, Peter Travers and Louise Jones. The money was raised at a quiz evening in November. We did put a team forward but I have heard nothing back so I can only assume that they didn't win. Many thanks to the Lions and all those who attended.



MS Helpline Freephone  
0808 800 8000

## Unexpected Change to PIP

On Thursday night (23/02/2017) the Government announced surprise changes to the Personal Independence Payment (PIP) assessment. We didn't expect these changes and are working hard to understand their potential impact. They follow proposals last year, which we and other disability charities sent a strong message against.

The planned changes will affect the way that someone's level of PIP award is calculated. They affect one of the ten 'daily living activities' (which determine eligibility for the daily living component of PIP), and one of the two 'mobility activities' (which determine eligibility for the mobility component of PIP).

The affected activities are Daily Living Activity 3 – Managing therapy or monitoring a health condition, and Mobility Activity 1- Planning and following a journey. The changes make these descriptors slightly more restrictive. They could impact the awards some people get.

We don't yet know the extent of the impact for people with MS. We're working to establish how likely it is that the changes will affect our community, and will keep you informed.

The Government believe these changes are necessary because of two Upper Tribunal judgements in 2016. They feel the rulings in these judgements broadened the way PIP assessment criteria should be interpreted beyond the original intention.

Our CEO Michelle says: "We're appalled by these restrictions. Less than a year ago the government promised people wouldn't lose any more support. Over one in five people with MS have already had their benefit downgraded after being reassessed from Disability Living Allowance. It's unacceptable that people are losing this vital support. Too often, people are relying on tribunals to correct inaccurate decisions.

"The system must be improved to make more sense. These changes will move eligibility criteria even further away from recognising the reality of living with an unpredictable condition like MS."

Published date: 24 Feb 2017

## Government Cuts to ESA

If the Government cuts ESA for new claimants by £30 a week, they must establish a plan to cover the additional financial support people need as a result of their condition, a committee of MPs has said today.

The cut is set to be introduced from April 2017, despite strong opposition in Parliament late last year to delay the change.

### 'Incentivise' the job search

The reduction will mean new claimants in the Work Related Activity Group (WRAG) will receive the same as people claiming job seekers allowance (JSA).

One of their reasons for the cut was that a reduction could incentivise people claiming the benefit, and who are deemed fit to work again at some point, to look for work.

But the report published today said the evidence for this was 'ambiguous at best'.

Our CEO Michelle Mitchell says: "Reducing financial support for disabled people won't help them into work, but instead is likely to affect their health and their ability to plan for the future, pushing them further away from employment.

"Disability benefits play a crucial role in helping people with MS, and other conditions, cover the additional costs they face. We want to see a welfare system that makes sense, and we'd urge the Government to rethink this cut which could have a devastating impact on people who rely on this vital support."

### Take action

The report also recommended that more emphasis should be made on incentivising and supporting employers to recruit and retain disabled people.

Published 3<sup>rd</sup> of February 2017

# The New Logo for MS Society



A complete change from logo's of old this is the new face of the Multiple Sclerosis Society in the UK

## Forthcoming Events

14th March	Social St Josephs Club Penketh 7:30 pm Bingo/chat
22nd March	Wigan Therapy Centre coffee morning Contact Louise 265239
3rd April	Chapelford 12 noon for 12:30 pm lunch Contact Peter 492970
11th April	Social St Josephs club Penketh 7:30 p.m. Bikes for All
8th May	Chapelford 12 noon for 12:30 pm lunch Contact Peter 492970
9th May	Social St Josephs club Penketh 7:30 p.m. Pets as a Therapy

Requests for transport - Jeff Richards 07738609018



0151 529 5645

Woolston Clinic  
2nd Monday of the month  
2 PM

MS Nurse Clinic

Support Your Branch  
Join the hundred+club  
Attend Socials  
Outings



## — Positive results from clinical trial of Ozanimod —

**P**ositive results from a late-stage clinical trial of ozanimod could make way for another effective multiple sclerosis (MS) treatment.

In the Celegen clinical trial, dubbed “Sunbeam”, two doses of ozanimod demonstrated statistically significant superiority over Biogen’s Avonex in reducing the annual relapse rate for patients with relapsing remitting MS (RRMS).

Ozanimod also bested Avonex by reducing the number of new brain lesions seen in MS patients. Celegene is conducting a second phase III study of ozanimod in MS patients, with results expected in the second quarter.

While most MS drugs have to be injected Ozanimod is dosed as a convenient pill. Ozanimod belongs to the same S1P modulating class of drugs as Novartis’ Gilenya.

Gilenya has tolerability issues, most notably a slowing heart rate which forces doctors to monitor patients after the first dose is taken. Ozanimod appears to sidestep heart-related tolerability issues, although additional data will be needed to confirm.

Celgene said the safety and tolerability of ozanimod in the phase III Sunbeam study was “consistent” with results from previously reported phase II studies. No further details were provided.

Multiple sclerosis has become an increasingly crowded and competitive market for drug companies and might be particularly vulnerable to pricing pressures. Celgene is developing ozanimod in other indications, including ulcerative colitis and inflammatory bowel disease. Celgene has not yet shared how it plans to move forward with ozanimod if the drug is approved, although the company has said it might build its own multiple sclerosis commercial team or seek out a partner.

Source: MS-UK (02/03/17)

## — SCT could have long-term benefits for some with MS —

**A**fter five years, progression had stopped in just under half of the 239 people eligible for the treatment. This means that half of those monitored did not experience worsening of symptoms, such as walking and swallowing, as measured by the Expanded Disability Status Scale (EDSS).

Researchers found that people without significant disability and those with relapsing MS who'd had HSCT at a younger age benefited the most from the treatment.

However, we need larger studies to better understand the impact of this aggressive treatment compared with existing therapies.

What did the trials involve?

This study involved 281 people with different kinds of MS, 78% of whom had progressive MS. Everyone involved had the stem cell therapy between 1995 and 2006.

HSCT is an intense chemotherapy treatment being developed for MS. It aims to stop the damage caused by MS by removing harmful immune cells. The person's own stem cells are then used to regrow the immune system.

The results are also a reminder of the aggressive nature of the treatment. Eight people in the study died as a result of the procedure.

### ***Who benefited from the treatment?***

The study showed that HSCT is most effective in people with MS who have 'active inflammation' in their brain and spinal cord.

Five years after the treatment, 73% of people with relapsing MS and 33% of people with secondary progressive MS did not experience any worsening of symptoms.

If someone has progressive MS but is still experiencing inflammation and relapses the treatment may be able to stop or slow this damage.

However, the treatment can't reverse damage that's already done. For people with progressive MS without inflammation in their central nervous system this treatment is not expected to help.

Researchers are working hard to find effective treatments for people with progressive MS.

Dr Sorrel Bickley, our Head of Biomedical Research, said:

"This study is one of the largest to date looking at HSCT as a treatment for MS and the findings offer some encouraging insights.

"There are more than 100,000 people with MS in the UK, it's a challenging and unpredictable condition to live with and that's why the MS Society is funding research like this to further our knowledge and find treatments for everyone.

"If anyone with MS is considering HSCT they should speak to their neurologist as a referral is needed to access this treatment via a trial or on the NHS."

Published 22 February 2017

## — Helpline piloting a change to their evening hours —

MS Helpline Freephone  
0808 800 8000

In recent months, the helpline has seen an unprecedented number of daytime calls and a drop in demand for the service after 5pm.

Currently we simply don't have enough staff and volunteers available to answer calls during this busy daytime period.

As such, from February, the helpline will run on new hours for a three month trial. This will see a reduction in our evening service, whilst increasing our daytime service.

During this trial the service will be available from 9am-7pm on Tuesday to Friday and will retain the current opening hours of 9am-9pm on a Monday.

# Executive Committee January 2017

## Branch Officers

Chair Mr Paul Harrison.....01606 892151  
Secretary Mrs Susan Bird.....659439  
Treasurer Mr John Burke .....824041

## Committee Members

Lead Support	Mr Peter Travers	492970
Fundraising	Mrs Julie Richards.....	573980
Joint Equipment/ Transport	Mr Jim O'Connor.....	451472
Web/DTP	Mr Jeff Richards.....	07738609018
Support	Mr Chris Janovitz.....	723564
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.

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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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