

Warrington Branch

MIScellany

December 2014

Seasons Greetings

*To all Members,
Families and
Friends.*



<http://warringtonms.org.uk>



MS Nurse Clinic

Carolyn Cairns

0151 529 5645

Woolston Clinic

2nd Monday of the month

2 PM

MS nurse - extra funding has been obtained to to put in place one more MS nurse to try and ease the appointment situation.

At one recent clinic (don't know which one) nearly half of the appointments did not attend. It's very hard to obtain funding for the MS nurses and failure to attend for appointments could result in the service being withdrawn and that would affect all who use the service.

It must be an age thing it doesn't seem like 12 months since the last Christmas party, but we are here again at Statham Lodge. MS is still with us, but there are three more licensed treatments for relapsing remitting MS than there was this time last year. There is also a push to advance treatments for progressive MS with research going on and collaboration between MS charities in USA, Canada, Italy, Australia, UK and the MS International Federation. Not sure yet as to how Primary Progressive MS is involved with this research.

Since the last newsletter we have three new members welcome to the branch. We currently have 174 members with MS which is the highest it's ever been. The reasons for this are numerous, but as the society reckon that only half of people affected by the condition join the society that could mean that heading towards 350 people in Warrington have MS.

There is not a lot else to report on at the moment, about 30 members returned to the Everyman for the rock 'n' roll panto on 29th of November. It was nice to see the theatre now that it has been completely rebuilt over the last three years. An enjoyable night was had by all the theatre has not lost any of its appeal the audience surrounding the stage on three sides. There was also an outing to Manchester Christmas markets on 3 December hope everybody had a good time.

Outings for next year hopefully will be decided on in January and should appear in our next newsletter which will be February, two months of 2015 past already.



**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:-

Graham BANKS	05-Dec
Liz SPENSLEY	08-Dec
Chris JANOVITZ	13-Dec
Stephanie ATHERTON	16-Dec
Mary BURKE	18-Dec
Jill SHERRATT	19-Dec
Margaret HUGHES	17-Jan
James WILDE	21-Jan
Betty TAYLOR	22-Jan
Jennifer CAIN	06-Feb
Karen DANIELS	06-Feb
Lorraine MORRIS	17-Feb
Nicola BROSTER	25-Feb

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

Listening Ear - Margaret Hughes -(01925) 723917

———— Tecfidera now available from the NHS ————

From today Tecfidera, a treatment for relapsing remitting MS, will be made available on the NHS in England and Wales; it is already available in Northern Ireland and Scotland.

Greater choice:- This means there are now 10 MS medicines available on the NHS for people with relapsing remitting MS - this time last year, just seven were available.

These new medicines include drugs that can be taken orally, as well as by intravenous infusion, and give people more options to consider when deciding what treatments are right for them.

Tecfidera is a pill that is taken twice a day and is proven to cut relapse rates and may also delay disability progression. It is considered to be more effective in reducing relapse rates and as effective for disability progression as existing beta-interferon treatments.

It is licensed across the UK to treat adults with relapsing remitting MS who have had two 'clinically significant' relapses in the past two years.

US authorities have recently warned that a patient with MS being treated with Tecfidera developed the rare and serious brain infection progressive multifocal leukoencephalopathy (PML), and later died. The drug's manufacturer, Biogen, estimate that around 100,000 people have taken Tecfidera, and this is the first reported case of PML in someone taking the drug.

As with all MS medicines, it's important to discuss your options and consider the potential risks and benefits with your MS specialist

Published date: 27 Nov 2014

———— Forthcoming Events ————	
Remember, there is no social in January	
21st January	Coffee morning Harvester Gemini 10:30 AM
10th February	Social St Josephs Club Penketh 7:30 pm
Requests for transport - Jeff Richards 07738609018	

Bessy's Blog

When I was a youngster, we would go to the seaside and I would become what Mary called 'Country Dog'. I think this meant running through puddles and chasing ducks across the marsh and other such foolishness. So when our holidays recently came around, I said to Dougy "We're going to the sea" "What's the C? You know I can't spell" "No, the sea. There's sand and waves to chase and if you drink the water, you get terrible wind". "I've already got terrible wind" he correctly added.

So we went to Norfolk and we went onto the beach to show him the North Sea. "Is that it? How do you switch it on?" he said before going back to the car. Isn't it typical of youngsters today? They just don't know how to make their own entertainment.

PS Dougy always asks me to check the Newsletter to see if he's won anything in the 100 Club. Fool! When will he learn.



PPS I know John tries his best with his new bells and whistles camera and I know uncle Chris will have tried his hardest to improve the one on the left but let's be honest it's not going to make the Countryfile calendar is it.

Message for Bessy. I know that really you are a good dog, but you have got to stop taking advantage of Dougy's inability to read and appropriating his winnings from the hundred+club. To advertise your dishonesty on this blog doesn't show you in very good light. I think it's time to get Dougy some reading lessons.

Uncle Chris

Disability Benefits in the News

The disability benefit Employment and Support Allowance (ESA) has featured heavily in the news in the last 24 hours.

While the BBC has reported leaked documents about the future of payments, a major announcement on the new company replacing the assessment provider Atos has also been made.

ESA payments to be reduced? Today the BBC has reported leaked documents revealing Government considerations for the future of ESA payments.

Internal documents reportedly suggest that thought has been given to reducing the rate of ESA for people placed in the Work Related Activity Group (WRAG) to a similar amount to Jobseekers Allowance.

People in the WRAG are recognised as being disabled but can be expected to undertake work related activity.

MS Society deeply concerned, Claire Nurden, Senior Policy and Campaigns Officer at the MS Society, said: "We are vehemently opposed to any reduction in the payments given to disabled people in the Work Related Activity Group of Employment and Support Allowance. This would represent a 30% reduction in payment to a group of people recognised as being disabled who face significant barriers to work.

"We are deeply concerned by the DWP's motivations for considering such a proposal – direct cuts in payments to disabled people must not be used to make up for costs incurred elsewhere".

The Department for Work and Pensions has said these proposals are not government policy. The MS Society will be discussing this issue with decision makers as soon as possible.

New assessment provider to replace Atos. It has also been announced today that American company Maximus is taking over the contract to assess ESA claimants. The previous assessment provider, Atos, was heavily criticised for its efficiency and methods of assessment.

Claire Nurden comments: "This new contract is a vital opportunity to improve the ESA process for disabled people. Significant changes must be made to both the contract and the way the Work Capability Assessment works to prevent the same mistakes being made by a new provider.

"The contract must include urgent improvements to improve accuracy. This means ensuring proper recognition of fluctuating and hidden symptoms, a much greater focus on evidence provided by professionals that know the claimant best, and appropriate awards for people with progressive

Published date: 30 Oct 2014

100+Club



There are 118 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 October 2014
Members 118

Prize	Num	Name
1st	047	Ann Hope
2nd	072	Louise Jones
3rd	097	Mary Barbour
4th	029	Jill Sheratt
	056	G Atkinson
	025	Jane Avery
	108	Pam Lilford
	100	J Wrenshall

The amounts were £118.00, £65.00, £39.00 and 5 at £10 respectively

11th November 2014
Members 118

Prize	Num	Name
1st	029	Jill Sheratt
2nd	002	LJ Allen
3rd	050	J Henthorn
4th	053	Dougie Burke
	082	Rita Harrison
	108	Pam Lilford
	098	Dilys Shenton
	069	Sylvia Rowles

The amounts were £118.00, £65.00, £39.00 and 5 at £10 respectively

MPs Must Cut Red Tape

The UK currently has no system where old drugs can be re-licensed for new purposes and drug manufacturers need to go through a lengthy application process if a drug shows promise treating a new condition.

In a front page story and letter in the Daily Telegraph, the MS Society and a group of neurological experts claim the current system is failing tens of thousands of people with MS, who might be helped by treatments currently unavailable to them.

As a result we are calling for an overhaul of current drug laws, to allow medicines to be “repurposed” to treat different diseases from those for which they were first licensed as there is evidence that a number of drugs could be effective in the treatment of MS.

For example, Simvastatin, a medicine originally licensed for treating high cholesterol, has shown in a recent phase 2 clinical trial to be effective in slowing brain atrophy in secondary progressive MS by over 40 per cent. Further phase 3 trials are required to demonstrate whether Simvastatin is both safe and effective in MS, but if these trials show positive results current licensing laws could prevent people from gaining access to the drug.

This Friday, MPs will debate the Off Patent Drugs Private Members Bill put forward by Conservative MP Jonathan Evans which aims to remove the bureaucratic hurdles, and could potentially help tens of thousands of people with MS.

MS Society Chief Executive Michelle Mitchell said: “There are over 100,000 people living with MS in the UK, and for many, treatment options remain limited. In progressive MS, symptoms gradually worsen and there are currently no medicines that can slow or stop the accumulation of disability. This can leave people desperate and willing to

Dave Hinde Travel Services



D.H.T.S.
Disabled Travel
Service

14 Seater Mini buses

Mobile 07887 615040

Parcel delivery service. Accounts

try anything and we know some even consider unproven therapies or interventions which might be expensive and dangerous.

“In the example of simvastatin, if phase 3 trials are successful, it would be cruel to tell people we have finally found a drug that might slow the progression of their MS but they cannot have it.

“This Bill proposes a fast and cost effective way to make new medicines available. It is nonsensical that people would be denied treatments that work because they are off patent. We urge MPs to help cut the red tape that prevents innovative treatments reaching the people that need them the most

Published date: 04 Nov 2014

Support Your Branch
Join the Hundred+ Club
Attend Socials
Outings

—Response to Fitness for Work Announcements—

A major independent review was published yesterday on the Work Capability Assessment – the test designed and used by the Department of Work and Pensions (DWP) to determine the entitlement of disabled welfare claimants to Employment and Support Allowance (ESA).

The Government’s appointed Independent Reviewer Paul Litchfield, released his final report recommending a series of changes to improve the process.

Meanwhile, the Government has outlined its plans for action in relation to harsh criticisms made by the Work and Pensions Select Committee earlier this year.

We believe the assessment process is deeply flawed and is failing disabled people, with devastating consequences. Claire Nurden, Senior Policy Officer at the MS Society and Co-Chair of the Disability Benefits Consortium, said:

“Wrong decisions can mean people are left with little or no support at all, in some cases struggling to pay for their homes and basic essentials like food and heating”.

“Significant changes need to be made urgently to stop disabled people suffering at the hands of the process as it currently stands. The test has to be more than a box-ticking approach and properly recognise the barriers many disabled people face in getting and staying in work.

“As things stand, this will be the last opportunity to shine a light on this broken test. Government should be committing to further independent reviews to monitor the impact of the test on hundreds of thousands of disabled people. All political parties must explain how they will improve the test if elected next year.”

Working together

The MS Society is part of the Disability Benefits Consortium (DBC) – a national coalition of over 50 different charities and other organisations committed to working towards a fair benefits system.

Using our combined knowledge, experience and direct contact with millions of disabled individuals and carers, we seek to ensure Government policy reflects and meets the needs of all disabled people.

We are working with the DBC to push the government for improvements to the WCA.

Published date: 28 Nov 2014

6 Mobility Telephone 01925 822411 To reserve Birchwood Shopping Centre	<i>Scooters available</i>	Coffee Morning 10.30am Harvester Gemini 3rd Wednesday of Month	
--	---------------------------	--	---

Campaign Shortlisted for Award

The MS Society's Treat Me Right campaign has been shortlisted for The Public Affairs Awards voluntary sector campaign of the year. Launched during MS Week in April 2014, Treat Me Right is calling for the right treatment at the right time for people with MS.

Poor access to treatments and information. We found that thousands of people were not getting the care they need when we surveyed over 10,000 people with MS in late 2012. There was also poor access to information about treatment options, which health-care professionals people should be seeing, and MS medicines.

The survey found that six out of 10 people with MS in the UK are not taking a medicine that can alter the course of the condition, despite being eligible. One in five had not seen their neurologist in the last 12 months.

Significant steps forward. Treat Me Right has already won widespread support with over 8,500 people signing up and 200 UK politicians pledging their support.

We called for considerable changes to the UK's National Institute of Health and Care Excellence (NICE) guideline for MS.

Media coverage and pressure from you, the MS community, meant that NICE heard our demands.

The final guideline, published in October 2014, includes a number of our recommendations, including that all people with MS should have a regular review with an MS specialist.

Treatments blocked, fight continues. Access to two progressive MS treatments, Sativex and Fampyra, was blocked by NICE on the grounds they were too expensive. We believe this analysis was flawed.

So the Treat Me Right campaign is keeping the pressure on NICE to conduct a more thorough assessment - to ensure that people with MS in the UK have access to the right treatments for them at the right time. Show your support for the campaign at www.treatmerightms.org.uk

Published date: 17 Nov 2014

Executive Committee May 2014

Branch Officers

Chair	Ms Amanda Wilton.....	726758
Deputy Chair	Mr Paul Harrison	01606 892151
Secretary	Mrs Elaine Magill.....	637120
Treasurer	Mr John Burke	824041

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
Support	Mr Chris Janovitz.....	723564
Activities	Mrs Rita Harrison.....	01606 892151
Social	Mrs Margaret Wilmot.....	755017
Subscriptions	Mrs Julia Wilton.....	726758
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:

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.

Charity number 1139257