

# Warrington Branch

# MiScellany

March 2010

Welcome to the latest edition of the MS newsletter. The weather is finally picking up, after an excruciatingly cold winter (as I can testify with early morning walks to the bus stop), and the heaviest snowfall for a generation, things are finally warming up.

I'm due to run a half marathon (number three) in April, this time in aid of my school's bursary fund. This means another battle to get fit in late night runs around Warrington, culminating in another punishing 13.1 miles along the coast in Blackpool. This is a fund of millions of pounds, which is invested, and the interest used to pay or help to pay for the school fees for boys at my school, purely on a means-tested basis. They also help to pay for school trips, and helped me to go on rugby tour to

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Sam King, 45 Denbury Avenue, Stockton Heath WA4 2BW Tel 860630

South America. Now in my final year, a group of us have got together to give something back and help boys in the future.

On the subject of school, I recently got my January module results, and I'm pleased to say that I've got two guaranteed As in maths, and only need low marks to achieve the rest of my offer for my university offer, so I'm practically guaranteed to get my place. These results included the AQA biology exam, which some of you may remember after it appeared on the news about two months ago, after thousands of complaints about the subject matter it didn't cover, and the lack of scientific knowledge tested. The unit was "scored" out of one hundred, which means that the raw marks are compared with all the other students in the country, and the top marks were awarded 100 points. Usually well over 90% is needed to get 100 points. For this exam, top students achieved 65%, showing how poor the exam was, and greatly misjudged. On this scale, losing 5 marks on the paper could result in going from an A to a C. Hopefully future exams will a fairer assessment of students.

Anyone who follows the Warrington Wolves will (currently) be enjoying a good season. After last year's victory in the challenge cup in Wembley, at time of writing they have played 5 matches and won four, putting them second only to Wigan, and even this is only due to point difference. Finally, the results of having Tony Smith (also the England coach) in command of the team are beginning to show. Another recent addition to the coaching team is Andrew Johns, one of the greatest half-backs of the current era. In 2005, when the team reached the Super League play-offs, he played for the Wolves on loan for a reputed £40,000 per game. He is now a valuable addition to what will hopefully be a successful season, provided the Wolves keep up the current pace.

Thank you for reading my piece. As per usual, please send any contributions to the usual email or phone number.

Sam King  
Samking91@hotmail.co.uk

Our congratulations to:-

Unfortunately at the moment we are no longer able to print birthdays in our newsletter. The same rule issued by headquarters will also stop the names of new members being included in the membership section of the newsletter.




This has arisen because a new member (not in the Warrington branch) made a complaint under the data protection act objecting to her name being included in her local newsletter without prior permission.

In future new members on joining the branch will be asked if they have any objections to being included in the branch newsletter.

Over the next few months you will be asked to sign a pro forma either giving your permission to be or not to be included. Alternatively e-mail me, [cj@warringtonms.org.uk](mailto:cj@warringtonms.org.uk) or visit our Facebook page which can be accessed via the branch website.

Chris Janovitz

Support  
Your  
  
Branch  
Attend Functions

Dave Hinde Travel Services  
  
**D.H.T.S.**  
Disabled Travel  
Service  
14 Seater Mini buses  
Tel. 01744 615851  
Mobile 07887 615040  
Parcel delivery service. Accounts

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<http://warringtonms.org.uk>  
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## 100+Club

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There are 107 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.

3rd of February 2010  
Members 109

| Prize | Num | Name        |
|-------|-----|-------------|
| 1st   | 082 | T. Dutton   |
| 2nd   | 088 | J Melbourne |
| 3rd   | 007 | K Critchley |
| 4th   | 030 | J Burke     |
|       | 003 | J Wolowicz  |
|       | 097 | M Barbour   |
|       | 015 | G Short     |
|       | 018 | P Travers   |

The amounts were £115.00, £63.00, G9£36.00 and 5 at £10 respectively

3rd of March 2010  
Members 107

| Prize | Num | Name              |
|-------|-----|-------------------|
| 1st   | 042 | J Wilde           |
| 2nd   | 002 | LJ Allen          |
| 3rd   | 081 | Rita Daly         |
| 4th   | 107 | Esther Thomas     |
|       | 036 | Cliff Sexton      |
|       | 106 | Maureen Maddocks  |
|       | 098 | Dilys Shenton     |
|       | 040 | Michael Errigadoo |

The amounts were £112.00, £61.00, £35.00 and 5 at £10 respectively

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## Membership News

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We have one new member but unfortunately since the last newsletter Josie Garvin died on 8 March her funeral on 18 March was attended by Dorothy on behalf of the branch. We have also been made aware since last newsletter that Stephen Nicholson died in December 2009 and Andrew Bate died on 29th of January.

We are a little short on space in this edition, it is hoped that before the next newsletter in May our problems with including any personal data about members i.e. name and birthday would be sorted.

Chris Janovitz

# Summer Planters and Hanging Baskets



**Contact  
Sam King  
(editor)  
01925 860 630**

**F**or the past few years I've gardened and sold hanging baskets and pots and troughs of bedding plants

This year I'm hoping to raise some money for university when I go this September, so I will be doing the plants on a larger scale this summer. There will be a range of sizes and pots to suit all gardens, and all are guaranteed to be bursting with colour.

A share of the profits will be donated to Warrington branch

All orders by 1st May, delivery will be available. Please give me a ring. Thanks for reading this.

Sam

## Exercise & Relaxation

**Great Sankey Library  
Marina Drive**

**Thursday at 11.30am**

Contact  
Mary Burke  
01925 824041

For details



## Elap Seat

A seat is available

Suitable For

Ford Focus

Donation Required

Contact Dorothy Lewis

01925 268820

**MS Helpline Freephone  
0808 800 8000**

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## Low-dose naltrexone (LDN)

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**W**hat is it? Naltrexone is licensed in the UK to help treat people who are addicted to opiates, such as heroin. Advocates of its use in MS suggest it should be given at a much lower dose than usual for the treatment of MS (10-50 times lower dose).

What does it do? Some research suggests that when naltrexone is given at low doses it triggers a prolonged up-regulation of endorphins. This increase may have an anti-inflammatory effect which could be beneficial in the treatment of MS. It has also been hypothesised that LDN may be able to reduce injury to the nervous system by decreasing the harmful effects of two types of chemicals called 'free radicals' and 'excitotoxins' (Med Hypotheses 2005; 64(4):721-4).

Does it work? In a small pilot clinical trial (Smith JP et al., American Journal of Gastroenterology; 2007 102(4): 820-8) LDN has been shown to improve active Crohn's disease, a condition which is caused by the immune system causing damage and inflammation to the intestinal tract.

At the 60th Annual Meeting of the American Academy of Neurology in Chicago in April 2008, two groups reported on the use of LDN. Dr. Gianvito Martino (San Raffaele Hospital, Milan, Italy) and colleagues assessed LDN in an open labeled trial of 40 people with primary-progressive MS for 6 months, evaluating its safety and tolerability. Five patients dropped out. A significant reduction of spasticity was measured at the end of the trial. The most common side effects included short-term increases in liver enzymes, urinary tract infections, mild agitation and sleep disturbance. This study was published in the September issue of the journal Multiple Sclerosis (2008 Sep;14(8):1076-83)

Dr. Bruce Cree (University of California, San Francisco) and

colleagues reported that eight weeks of treatment with LDN significantly improved quality of life (specifically, mental health, pain, and self-reported cognitive function) in 60 people with MS as measured by the MS Quality of Life Inventory. No impact was observed on physical quality of life (such as fatigue, bowel and bladder control, sexual satisfaction, and visual function). Vivid dreaming was reported during the first week of treatment, but no other adverse side effects were reported.

There is a study which began in early 2007 at the University of California which involving 80 people with MS looking at the effects of LDN on quality of life in people with MS.

In May 2007 the MindBrain Consortium and the department of psychiatry of Summa Hospital System of Akron in Ohio announced a new scientific study of the effects of treating 36 people with progressive or relapsing MS with LDN. The study aims to look at symptom severity as well as changes in quality of life and sleep patterns.

Should I take it? Currently there is not enough evidence-based information to prove LDN is an effective treatment for MS. The results of these small pilot studies are an important step in determining if there is any benefit for people with MS and the MS Society welcomes this research.

LDN is not licensed for the treatment of MS in the UK. Some people with MS in the UK may have been prescribed LDN by their own GPs; however many GP's are reluctant to prescribe LDN in the absence of phase III clinical trial evidence that the drug is clinically beneficial.

The decision to take LDN is a matter for individual judgement, though people are advised to 'err on the side of caution' until the safety and effectiveness is fully established.

MS Society 1st of March 2010

## Trial Results for LDN

Results of a phase II clinical trial on the safety and effectiveness of low dose naltrexone (LDN) as a symptom-relief treatment for people with MS have been published in the journal *Annals of Neurology*.

The results of the study suggest that LDN is safe and may have positive effects on the mental quality of life in people with MS; but no effect on a patient's physical quality of life.

The work, led by Dr. Bruce Cree at the University of California in San Francisco, is the first placebo controlled clinical trial to look at the effects of LDN in people with MS.

Researchers found vivid dreaming was the only symptom reported as a result of taking LDN but due to a high drop out rate among trial participants, concluded that larger scale trials are needed to determine the effect of LDN on overall quality of life.

Dr Susan Kohlhaas, Research Communications Officer at the MS Society said, "We are really pleased to see results of this study published. The next step will be to complete larger, more detailed clinical trials to determine the potential of LDN as a symptom relief therapy for people with MS."

01 Mar 2010

| Forthcoming Events                                 |                                       |
|--|---------------------------------------|
| 7th April  | Social Alford Hall 7:30 p.m.          |
| 17th April   | Ryfields coffee morning 10 a.m.       |
| 5th May  | Thank You Party Alford Hall 7:30 p.m. |
| Requests for transport - Jeff Richards 07738609018 |                                       |

Listening Ear - Margret Hughes - 01925 723917

## Drugs Update

**S**ativex(cannabis spray) is one step closer. The regulatory process is marching on, the UK and Spanish regulators have agreed that there are no major quality, safety and efficacy issues outstanding. Still remaining is the wording on the patient information leaflet which is expected to be reviewed in the coming weeks.

Once the final wording has been agreed the process enters its final stage which takes place in the individual countries. When completed the spray will be available on prescription for the treatment of spasticity caused by multiple sclerosis.

GW Pharmaceuticals expect approval in the UK during the second quarter of 2010

**B**ioigen have disclosed that there has been seven more cases of the rare brain infection (progressive multifocal leukoencephalopathy, PML) in MS patients using Tysabri bringing the number to 42. Another patient using the drug has died bringing total deaths to 9. The number of cases reported is important as increases will affect take-up of the drug.

Tysabri is believed to be a highly effective therapy for MS. In January in the USA the Food and Drug Administration provided an update that noted an increased risk of contracting the brain infection but it concluded that the benefits of the medicine continue to outweigh the risks.

The drug was withdrawn for a period of 18 months starting in 2005 because of the risk of contracting PML.

Source MS Society

Kerry

*Clinical Nurse Specialist in M.S.*

Woolston Clinic

2nd Monday of the month

Tel Dorothy Lewis 268820

for Appointment



## — Employment and Support Allowance (ESA). —

ESA was introduced in October 2008 to replace the existing incapacity benefit for new claimants. It aims to give more help to those who might, with support, be able to work.

The CAB have been monitoring the implementation of ESA, and advisors have been reporting high numbers of seriously ill and disabled people being found 'fit for work' under the new assessment criteria.

The report highlights particular problems for people with long-term fluctuating conditions, like MS, and found the assessment fails to take account of variable symptoms and shows little recognition of fatigue, pain and general exhaustion.

The report 'Not Working - CAB evidence on the ESA Work Capability Assessment' outlines concerns and makes a number of key recommendations, including:

The range of exemptions for the assessment should be extended (for example, people with 'a severe and progressive neurological disease' were previously exempt from assessment and automatically eligible for Incapacity Benefit, but are not for ESA)

Decision-makers should have the power to make a decision for a short period on the basis of written evidence from the claimant's own doctor, and such evidence should be more routinely gathered.

An additional 'real-world' test should be brought into the assessment

The guidance to healthcare professionals should be urgently reviewed

Results of the assessment report should be routinely sent to claimants, who should be given the opportunity and time to correct inaccuracies

Research should be undertaken as a matter of urgency into the reliability of the Work Capability Assessment for ESA.

Laura Weir, Head of Policy Campaigns at the MS Society, said: "It is extremely concerning that hidden and fluctuating symptoms of MS that can make it impossible for people to work are not being considered or recognised in the assessment process. The recommendations in this latest report must be taken forward as a matter of urgency."

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<http://warringtonms.org.uk>  
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## Activity & Social

### Dates for your diary

- April 9, 10 Open Day Longlane garden centre.  
April 12 Luncheon Club, Evenwood Farm, contact Peter 492970  
April 17 Ryfields coffee morning  
May 8 Brindley Theatre Runcorn (C'mon Everybody)  
Seats to be confirmed by early April (01925) 755017  
May 10 Luncheon Club, Evenwood Farm, contact Peter 492970  
Long Lane garden make your own hanging baskets contact Rita Daly 815873  
May 20 Garden Centre visit Longlane, make your own hanging baskets  
May 23 Sponsored Walk contact Chris (01925) 723564

Contact Margaret on (01925) 755017 unless otherwise stated or with any other ideas you may have for the activity group.



### Calling All Crafters

**W**e're going to try to get a craft group organised. We have helpers who are quite proficient in knitting, sewing, patchwork, beading and card making.

If your interested in any of the above then please contact either Margaret on 755017 or Helen on 723564. If there is enough support times and a venue will be discussed then.

Whilst we're on crafts if any of you have broken or unwanted bead jewellery and would like to donate it to the branch were it will be recycled and then sold to help branch funds.

# Executive Committee April 2010

## Branch Officers

|                 |                        |              |
|-----------------|------------------------|--------------|
| Chair           | Mr Paul Harrison.....  | 01606 892151 |
| Secretary       | Mrs Elaine Magill..... | 637120       |
| Treasurer       | Mr John Burke.....     | 824041       |
| Support Officer | Mrs Dorothy Lewis..... | 268820       |

## Committee Members

|                               |                          |              |
|-------------------------------|--------------------------|--------------|
| Fundraising                   | Mrs Julie Richards.....  | 573980       |
| Joint Equipment/<br>Transport | Mr Jim O'Connor.....     | 451472       |
| Web/DTP                       | Mr Jeff Richards.....    | 07738609018  |
| Social                        | Mr Chris Janovitz.....   | 723564       |
| Everybody's Help              | Mrs Rita Harrison.....   | 01606 892151 |
| Activities                    | Mrs Suzan Rainford.....  | 602719       |
| Editor                        | Mrs Margaret Wilmot..... | 755017       |
| Subscriptions                 | Mr Sam King.....         | 860630       |
| Everybody's help              | Mr Peter Travers.....    | 492970       |
| Yoga & Exercise               | Charles Dooley.....      | 860112       |
|                               | Mary Burke .....         | 824041       |