

Warrington

MiScellany

October 2010

Tomorrow (today is the first of October), I go down to Oxford to study Medicine, and I've spent the last twenty four hours packing an unbelievable number of things. I honestly didn't realise that my survival for the next eight weeks depended on so many things.

Nine banana boxes; a humongous hold-all on wheels, so full of books that cornering is pretty much non-existent; a smaller hold-all; rucksack; shoulder bag; and finally an industrial sized bin bag full of bedding. Bear in mind that my college room already has furniture, bed, etc, and there's a shared kitchen with pans and utensils. So I'm not quite what is actually in all the boxes, apart from enough dried tinned otherwise long-life food to sustain the average family of four for that amount of time.

Never mind the fact that I get five evening meals per week cooked for me, and I probably won't be there every other weekend. Although I suppose it will be ok, I have so many people coming to drop me off (nine) that ten trips per person should just about empty the car. I'll just introduce myself as distant royalty, complain about the lack of fanfare, and that should explain the entourage.

More seriously, recently the national MS society has been

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

in the news, for a proposed vote of no-confidence against the society. This after the board voted to stop providing respite care services in four centres in York, Surrey, East Lothian and Leamington Spa. However, the vote of no confidence received support from only 30% of the 7000 members who took part in the vote. In contrast, 60% of voters backed the resolution to uphold the board's decision to withdraw the respite services. The society will be meeting to discuss alternatives to those services being withdrawn. The official statement from the MS society was: "We are pleased that members have voted in favour of the society's decision to update the way in which we provide respite care. The current four centres are excellent but are not used by the overwhelming majority of people with MS who need respite care."

Finally, my last editorial was just too early to incorporate the Challenge Cup Final at Wembley. As everyone in Warrington knows (or at least should know!), Warrington won their second challenge cup final in a row, a feat they have never managed before, against Leeds Rhinos, the 2009, 2008 and 2007 Super-league Grand Final winners. Despite losing against Leeds in both their league fixtures, Warrington crushed the Rhinos 30-6. I took the trip down by coach with my dad; the atmosphere was amazing. However, their Super League hopes left much to be desired, when Warrington lost both their opportunities to enter the semi finals, disappointingly losing against a much weaker Huddersfield side. Captain Adrian Morley also lost out on the title of Man of Steel to Wigan's Pat Richards. However, with some new signings for next season (including Brett Hodgson from Huddersfield, 2009's Man of Steel); a solid league finishing position of 3rd place; and a double challenge cup win, Warrington have a lot to build on for the 2011 season.

Sam King

**Support
Your
Branch
Attend Functions**

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MS Helpline Freephone
 0808 800 8000



Please complete the form allowing us to disclose your birthday, show photographs & say whether you have MS or not and return in the envelope provided it will require stamp unfortunately. You could also include your meal choice for the Christmas party.

Chris Janovitz



————— Forthcoming Events —————

9th November	Pirate night social St Josephs Club 7:30 pm
25th November	Bellevue dogs racing
5th December	Christmas party Paddington House 12.30pm
11th December	Everyman rock panto

Requests for transport - Jeff Richards 07738609018

Listening Ear - Margret Hughes - 01925 723917

100+Club

There are 108 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.

4th of August 2010

Members 109

Prize	Num	Name
1st	110	Roger Williams
2nd	037	Betty Taylor
3rd	054	Bill Hampson
4th	022	A G speed
	042	Jim Wilde
	043	Stephanie Atherton
	099	Janet Wrenshall
	087	John Curley

The amounts were £109.00, £59.00, £33.00 and 5 at £10 respectively

14th of September 2010

Members 109

Prize	Num	Name
1st	064	Helen Janovitz
2nd	016	Barry Daniels
3rd	001	John Burke Snr
4th	020	Mary Burke
	050	Joan Henthorn
	072	Frances Mulcahy
	085	M Richards
	097	Mary Barbour

The amounts were £109.00, £59.00, £33.00 and 5 at £10 respectively

Activity & Social

We are looking to see if anyone is interested in a day out to the East Lancs Railway at Bury there are lots of things to see and do apart from a train ride to Ramsbottom there is a carriage which can accommodate wheelchairs, ramps etc.

If we have enough interest for this trip we will make arrangements for transport if needed and a date to be arranged.

Turkey & Tinsel break. Unfortunately due to a very popular location we are unable to book the date mentioned 22nd - 26th November as a group booking.as the hotel is fully booked for those dates.

Please contact Margaret 755017

Stem Cell Doctor 'struck off'

A doctor who injected people with MS with stem cells not fit for human use has been banned from work.

Earlier this month the GMC ruled Dr Robert Trossel's fitness to practice was 'impaired' after he treated several of his patients with unlicensed stem cells intended only for laboratory use. Today the council have ruled he should no longer be allowed to practice medicine.

The GMC believe he "exploited vulnerable people" at his clinic in Holland by charging thousands of pounds for treatments for which he had little evidence would work.

Simon Gillespie, Chief Executive of the MS Society, said: "We're pleased with today's outcome which is a success not just for the medical profession, but more importantly for people with MS. We've consistently warned of the dangers of unproven stem cells treatments as there is no way of knowing for sure the credentials of those carrying out the procedure or the health risks involved."

The GMC's inquiry into Dr Trossel's practice was sparked by an investigation by Newsnight. Tonight the investigative news programme follows up on the case, and includes an interview with Simon Gillespie.

MS Society 29th September

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

WANTED Used Postage Stamps
Odd Balls of Wool
Contact Susan Atkinson
Tel. 727612


Spare Spectacles
Contact Susan Atkinson
Tel 727612



—— Suspending the Board's respite care decision ——

Members' resolution. Board suspends its decision on Respite Care in the absence of appropriate alternative provision for those severely affected by MS: future decisions will be ratified by a majority of members.

Result of the ballot

For: 2461

Against: 3756

This resolution was declared as not carried.

Proposed by: Susan Tilley Former Trustee, and former assistant national treasurer of the MS Society. Seconded by: RG Bricknell

Supporting statement The decision is flawed because:

- It reduces choice for the most vulnerable
- Only 1% of members were consulted
- Participants views were misrepresented
- Users of centres were inadequately consulted raising serious concerns amongst members
- The range of future options considered was too narrow
- Personalised budgets are immaterial if there is nothing of quality and relevance to spend it on
- It betrays the bond between centres, branches and the communities
- Irreplaceable centres of excellence tailored to the need of PwMS are lost

The Society's greatness is measured by how it treats its weakest members.

Board's response The respite care review was signalled in the Society's Strategy, ratified by members in 2008. 32% of respondents surveyed were people who currently use the Society's respite care centres. Their views were deliberately over-represented in the survey - one element of the review. People with the highest dependency needs are the smallest group using our services, mainly living in close proximity to a respite centre. Vulnerable people in other parts of the UK receive no support from the Society. People with MS want the Society to use its resources more equitably, enabling more people to access short breaks or respite.

—— Vote of no confidence in the Board of Trustees ——

Members' resolution. Members no longer have confidence in our Board. They have betrayed members' trust by redirecting major respite care spending without our approval. Key decisions should be brought to the members.

Result of the ballot:

For: 1810

Against: 4101

This resolution was declared as not carried.

Proposed by: Janice Cook Former Trustee, and former vice chair of the MS Society. Seconded by: Susan Tilley Former Trustee, and former assistant national treasurer of the MS Society.

Supporting statement. The MS Society has a long history of putting people affected by MS at the centre of its decision-making. Hiding behind legal advice that it is not necessary to go to the AGM on this significant issue is despicable and signals an intolerable sea change in the Society.

What's the next decision the Board makes behind closed doors: removal of research funding, deletion of branches?

The Society should be an exemplar of inclusivity by allowing their members to make an informed choice. Members should be empowered and given the opportunity to speak and decide on vitally important issues.

Board's response. To keep people affected by MS central to their decision making, the Trustees instigated an extensive 18 month respite care review to canvass opinion through membership magazines, TeaMSpirit, the website, via respite care centres to staff (including face to face meetings), volunteers and guests.

People with MS and their carers have been part of every aspect of the review, from overseeing the survey to planning stakeholder events. The Trustees, the majority of whom live with MS on a daily basis, have reflected these views in their decision and remain committed to promoting the very best interests of people affected by MS.

— Cladribine - MS tablet unlikely to be available in UK —

An influential committee for the European Medicines Agency (EMA) has decided the risks of Cladribine, an effective oral treatment for relapsing remitting MS, outweigh the potential benefits.

Cladribine is an oral tablet for MS that has just undergone the final phase III trial.

Cladribine was shown to:

- reduce relapses by 60 per cent over a two year period
- reduce disability progression by 30 per cent over a three month period

Unless the EMA reconsiders its position, it is unlikely that this innovative Cladribine will be made available on the NHS.

What does the MS Society think?

Dr Jayne Spink, Director of Policy and Research at the MS Society said: "This decision is very disappointing. We hope that a way forward can be found and that the regulators will make every effort to take full account of the views of people with MS."

In a survey we ran with over 1000 people affected by MS, 95% said they would prefer to take a pill to treat their MS. The physically debilitating and unpredictable nature of relapses means that many people would consider a small degree of risk acceptable, as long as they are aware of all the potential risks involved.

What happens next?

The MS Society will find out more from the EMA about why they made this decision. We've presented evidence to this particular committee before, and we'll be seeking reassurances that the committee have taken the perspectives of people living with MS into account

Respite Centre Survey Summary

Thank you to the 35 members who responded to this survey. While this number represents only between a quarter to a third of total membership (difficult to be precise with central records), it reflects a high response level for a mail survey.

- § 69% of respondents disagreed with the decision of the MS Board to dispose of the Respite Care Centres;
- § 74% felt there should be no change to current provision;
- § 54% felt that service provision at the four centres was sustainable and reflected user needs and aspirations;
- § 66% felt the Society should continue to focus resources on running centres.

This decision by the Board has, however, since been supported at the Society AGM. Respondents did agree, however, with other proposals which arose from the Respite Consultation;

- § 66% would wish to expand the then current respite model;
- § 89% would wish to improve efficiency in care centres;
- § 66% would wish for some re-design and re-focus of the current model;
- § 63% would like to develop access to services nationally by way of partnerships.

In summary it does look as though respondents do generally support the overall model and direction proposed by the Board and accepted at the AGM 2010, apart from the important issue of ownership of the four centres.

I am sure that there is sufficient agreement to allow us to play a full part, with the Board, in taking these matters forward.

Paul Harrison
Chairman

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<http://warringtonms.org.uk>
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Membership News

Since last newsletter we have two new members welcome to the branch to you both and we have recently been informed of the death of Mrs M G Strong earlier this year.

What a month the MS Society making BBC News and not particularly in a good light. I'm afraid that like many others I believe that the MS homes are being disposed of for financial reasons rather than the stated "it's what our members want." I have been to both Leamington Spa and York I think about seven times between the two of them. I find it hard to believe that the quality of the care provided at these establishments will be equalled outside of this arena. Is supporting them not one of the things we raise funds for. I suppose now we will just have to wait and see what happens.

The Christmas menu is with this newsletter and I hope that many of you will attend. To help Dorothy Lewis who has organised this in the past I will be responsible for collating all the menus. I have included an envelope for the return and I will acknowledge receipt with a telephone call. I know the cost has risen but this has been unavoidable. All members who attend (excluding executive committee) will be entered into a draw for a litre bottle of spirits (either gin, rum, vodka or whiskey) or £15 cash. The noticeboards will also be available at the party for displaying Christmas cards from members who have made a donation to the branch in lieu of giving individual cards

Also included (unless you've already signed one) is the data protection form for you to sign that will allow your birthday and if needed at some point your photograph and whether or not you have MS to be used by the branch in materials publicising the branch. Please use the envelope provided.

Susan Atkinson has approached me to ask you for used greetings cards to cut up and make gift tags. Give her a ring on 727612

Chris Janovitz

The MS Society has committed to funding 12 new research projects costing more than £1.6 million.

What we're funding

The funded projects fall under four broad categories spanning:

Cause – research looking at the causes of MS

Cure – research to develop better treatments for MS

Services – research to improve services for people with MS

Symptoms – research to improve symptom management for people with MS

Below is a sample from each of the above groups, the full list is available on the society's website.

Grant #935: Analysis of pathogenic and regulatory T cells in relapsing-remitting multiple sclerosis

Grant #939: The role of blood components in axon injury in Multiple Sclerosis: new opportunities for neuroprotection

Grant #933: The Mii-vitaliSe study: A pilot randomised controlled trial of a home gaming system (Nintendo Wii™) to increase activity levels, vitality, and well-being in people with MS

Grant #930: Development of "Mums + MS": A public access web site hosting an interactive self management intervention for women with multiple sclerosis who are contemplating pregnancy: modelling phase

Gentle exercise in a swimming pool

If we get sufficient numbers we could
have the pool to ourselves

We had one session already

Contact Charlie Dooley on 860112

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/ 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
Everybody's Help	Mrs Mary Burke.....	824041
Everybody's Help	Charles Dooley.....	860112
Everybody's Help	Mary Burke	824041

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: Sam King
Layout 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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