MULTIPLE SCLEROSIS SOCIETY SUTTON COLDFIELD & DISTRICT BRANCH

MS Multiple Sclerosis Society
Charity No. 207495

MiScellany

SUMMER 2007



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If you have any comments about this or any other publication of MiScellany or wish to put in articles or items please don't hesitate to contact the Editorial Team.

Mike Shaw - 0121 686 2415 ***Vicky Pennicott - 0121 686 6523***

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HOMEPAGE

KEY TO PHOTOGRAPHS ON FRONT PAGE

1 MIKE AND CLARE IN FLORIDA LOOKING AT SKYCOASTER.

2 MIKE AND CLARE. CLARE DECIDING SHE WAS MAD AFTER ALL

3 CLARE SUSPENDED AFTER A 300 FOOT DROP AT 100 MILES AN HOUR !!!!!!!!

4 JULIE MARROWS BEFORE RUN (FULL OF ENERGY)

5 JULIE MARROWS AFTER RUN (SHATTERED)

6 CAROLYN AND SUE IN THE MONKEY HOUSE !!!!

7 SIMON GILLESPIE (CHIEF EXECUTIVE) JAYNE AND JULIE ATTENDING ADDENBROOKES FOR UPDATE ON RESEARCH PROGRAMME see pages 8/10.

8 LABORATORY AT ADDENBROOKES HOSPITAL, CAMBRIDGE.

9 RESEARCHER AT WORK

PHYSIOTHERAPY

A free advice session is being offered by the Physios on Monday 3rd September at Clifton Road. If there are any questions on exercise or mobility issues these are the people to ask!

See Diary Dates

HAPPY BIRTHDAY

JULY

7th	SYLVIA BARRETT
13Th	NICHOLAS JACKSON

AUGUST

1st	JAYNE ROBINSON
2nd	LESLIE HALL
6th	JENNIFER JACK
13th	KAREN FISHER
13th	STAN POVEY
16th	DEE DUNSTAN
27th	SUE BOND

SEPTEMBER

3rd	MELVYN EVANS

TWYCROSS ZOO

Everyone who attended this Regional Event had a thoroughly enjoyable time.

Our members as you can see from the photograph spent an awful lot of time with their peers (the monkeys).

We retrieved them after complaints from the inmates.



HOMEPAGE (CONTINUED)

Clare (Mike's P.A.) was very brave and went all the way to Florida to do a Sky Coaster Jump!!! She raised in the region of £200 for the branch.

I am sure she could have done this at Drayton Manor, but what the heck, the one in Florida is the biggest in the world at 300 foot.

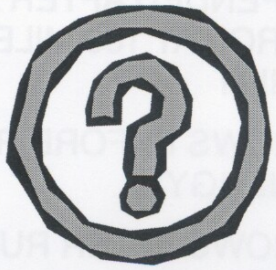
Julie Marrows (Nicks Wife) completed the Great Midlands Fun Run, 8.5 mile in 1 hour 20 minutes and 45 seconds. She has also raised £200 for the Branch.



WELL DONE TO YOU BOTH.

JULIE FOR RUNNING

CLARE FOR JUMPING.



SORRY

NO PICS OF DEATH WISH ACTIVITIES

MS COLLECTING

The round of Collecting dates in and around the area are starting soon, so we will be requiring your help.

Any time you can spare to come along and help will be greatly appreciated.

These are the dates SO FAR !!

July 7th - Sainsburys Mere Green

July 21st -The Mall. Gracechurch

August 3rd -Red Rose Centre Sutton

August 4th-Red Rose Centre Sutton

Please keep your eyes on the

DIARY DATES !!

354 8593

S.O.S

Our request for help at the Clifton Road Centre still goes out !

We are still looking for someone who is ambulant and can assist in opening and/or closing the Centre. Times are 10am till 2pm.

PLEASE

Contact the centre on 354 8593

MULTIPLE SCLEROSIS SOCIETY
SUTTON COLDFIELD & DISTRICT BRANCH

MONTHLY BRANCH MEETINGS

1st Wednesday of every month at 7.30 p.m.

Westfield Court Hotel

Birmingham Road, Sutton Coldfield

ADVICE & INFORMATION CENTRE

Monday and Friday 10.00am 'til 2.00pm

Clifton Road Youth Centre

Clifton Road

Sutton Coldfield B73 6EB

0121 354 8593

email :- suttonms@hotmail.com

Website : - www.mssociety.org.uk /branches/ west_midlands / sutton_coldfield/

COMMITTEE 2007-8

CHAIRMAN	Julie Leeson	0121 308 4089
SECRETARY	Pauline Commander	0121 382 1385
TREASURER	Jayne Robinson	0121 308 5641
SUPPORT	Ann Forbes	0121 384 3639

Other Members

Assistant Treasurer	Nick Beedle	
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Bulletin	Vicky Pennicott	0121 686 6523
Member	Sue Foster	0121 686 1297
Member	Dee Dunstan	0121 686 6476
Member	Paul Dunstan	0121 686 6476

CARAVANS

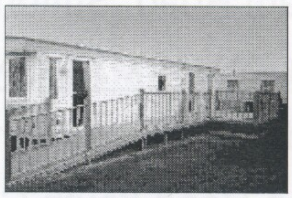
*Further to our article in our October issue of MiScellany.

Caravan users are now known as **"PAMS"** = People Affected by MS or **"Others"** = Everyone else

WESTON-SUPER-MARE

Rates for PAMS*

UNITY FARM	
April	170.00
May	180.00
June	195.00
July	210.00
August	210.00
September	195.00
October	195.00





Rates for Others*

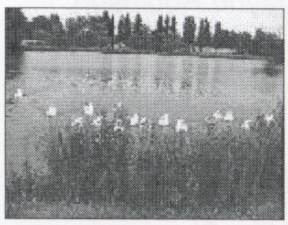
UNITY FARM	
April	270.00
May	280.00
June	295.00
July	320.00
August	320.00
September	295.00
October	295.00

NORTHAMPTON

Rates for PAMS*

BILLING	
April	95.00
May	95.00
June	95.00
July	105.00
August	105.00
September	95.00
October	95.00





Rates for Others*

BILLING	
April	155.00
May	155.00
June	155.00
July	165.00
August	165.00
September	155.00
October	155.00

Bookings can be made at The Clifton Road Centre **ONLY**

(see page 5 for opening times), where a deposit will be required.

For bookings contact 354 8593 (MS Centre)

DIRECT PAYMENTS

As you are aware the Social Services allocate the care that is required to either their own employees or in the case of 'double-ups', they allocate to an Agency. The Agency then charges direct to Birmingham City Council Finance Department and we do not get involved in the financial aspect at all.

But think about it! When the agency staff do not turn up what happens? The Agency is still paid. In one week alone I estimated that the Agency was paid £144 for hours not worked. **THIS IS OUR MONEY PAID IN TAXES. – NO WAY, WE PAY ENOUGH, SO LETS LOOK AT SOMETHING DIFFERENT. DIRECT PAYMENTS.**

Our Social worker arrived to discuss the matter. We also required extra funding which was approved and obtained through the Independent Living Fund (ILF). Having discussed the matter it was agreed that we would go down the Direct Payments route. We could use an Agency authorised by the Council, Penderels Trust but we decided to do this ourselves.

Set up a separate Bank Account – to ensure a tight control of monies in and out

Employ either Penderels (free) or a firm of Accountants

Register as an Employer if you are doing it yourself

Research Health and Safety issues, Employers Liability Insurance etc (Penderels will help)

Suddenly we were in control of getting the best possible care for Mike on our terms, we could monitor hours worked, agree payments for genuine hours worked. Discuss every stage with your Social worker. It may take a few months but honestly it is the best way forward. There is always someone to help and advise you, from the finance officer at the council, your social worker to the ILF's Advisor. We did at this stage 'ditch' the Agency and employed 2 PA's.

You also have to supply detailed records every three months, however you can use Penderels to do this if you want. We don't. We keep a spreadsheet of all payments in and out and I am happy to show these to anyone interested, it is very simple.

The Benefits are enormous. You know how many hours a week you are being paid for, you can then use this to suit your needs entirely. For instance you normally have someone for 4 hours a day, but 1 day you only need 2 hours, you can 'save' these 2 ours towards another day if you require 6 hours. It's the flexibility of it all which works. It gives Mike the freedom to do what he wants when he wants.

I must emphasis that this is strictly monitored both by the Finance Department and the Independent Living Fund and can only be used for personal care. Should you go on holiday with your carer you **cannot** pay from the Account for their travel or their accommodation but you can pay for extra hours (if you have sufficient in the Account) for them if you require extra care away from home. You also do not receive any monies from the Council or ILF when you go into respite care. You also **cannot** pay anyone who lives at the same address as you and you cannot 'dip' into these monies to use for any other use. ILF provide leaflets and these can be downloaded through their web site. There are strict guidelines and if you do not abide by them then the monies are withdrawn.

Please do not hesitate to contact me direct if you require any further information or assistance.

Liz Shaw

MS Society Cambridge Centre for Myelin Repair

Mission statement

The mission of *MS Society Cambridge Centre for Myelin Repair* is to develop new therapies for promoting myelin repair and preventing nerve fibre loss in MS patients. The centre unites existing expertise in stem cells, brain repair and MS in a focused programme of work.

Background

The brain contains billions of nerve cells that communicate with each other using electrical impulses. The conduction of these impulses requires an insulating substance called *myelin*, which is made and maintained by a cell called the *oligodendrocyte*. In MS oligodendrocytes and their myelin sheaths are destroyed. In the early stages of the disease they are replaced by oligodendrocytes newly generated from *stem cells* (sometimes called *precursor cells*). This process is *remyelination*, which is highly beneficial and associated with clinical improvement. However, as the disease progresses remyelination fails. This means that full function is never regained. A further serious consequence of this failure is that the nerve fibres themselves can be lost, a process that causes the progressive decline in the late stages of the disease and from which there is no recovery. Enhancing remyelination is therefore imperative for two reasons – 1) it allows nerve fibres to function normally by repairing existing damage and 2) it prevents nerve fibres from being lost, thereby preventing chronic deterioration.

The treatment of MS is two-pronged. First, it is important to stop the inflammation causing the myelin loss. Medicine has made significant progress in this direction with the development of treatments such as beta-interferon and CamPath (a treatment developed in Cambridge). Second, it is essential to promote repair of damage that has occurred. At present, there are no repair treatments available, representing a major and significant gap in our ability to treat MS. However, recent developments in our understanding of MS and brain stem cells, together with new technological developments, combine to make the present the appropriate time for a concerted effort to develop effective repair treatments for MS patients.

The research programme

The work programme of the Myelin Repair Centre will involve a series of studies that will 1) identify the factors that allow stem cells to undertake myelin repair so that these factors can be used as a treatment to promote repair where it has failed in the disease, 2) reveal how nerve cells respond to the loss and restoration of the myelin sheaths so methods for protecting nerve fibres can be designed and tested, and 3) test the ability of different CNS stem cells to protect demyelinated axons, either by covering them in new myelin sheaths or by providing protective substances.

Progress so far

1) Recruitment

The Centre has seven new posts associated with it; four post-doctoral scientists, two research assistants and a secretary. Recruitment constituted the first phase of the programme which officially started in April 2005. This was a crucial phase since we were anxious to recruit the best people we could possibly find since the success of such programmes is largely dependent on the quality of the researchers employed. Not all the new recruits were able to start at the same time so the programme had a 'rolling start', which is inevitable when so many new post need to be filled.

Dr Jeff Huang joined the Centre in October 2005. Dr Huang trained in the USA in a well-known and prestigious myelin laboratory in New York. Dr Chao Zhao, a senior and highly experienced researcher joined the Centre last year. Dr Zhao had previously worked on an MS Society funded project led by Profs Franklin and ffrench-Constant. Dr David Hampton also joined the Centre last year, returning to Cambridge, where he did his PhD with Prof James Fawcett, from a position in Vancouver, Canada. Dr Andrew Jarjour also joined us from a lab in Canada, where he has recently completed his PhD at the famous Montreal Institute of Neurological Sciences. Dr Karen Irvine, who did her PhD in Cambridge with Prof Bill Blakemore, stayed on to work at the Centre for the last two years but has now left for a new position at the University of California at San Francisco. An excellent scientific team is complemented by the recruitment of Kim Wolstenholme, who is the Centre's administrator.

2) Scientific progress

Despite the rolling start caused by the staggered recruitment and the consequent difference in when each component of the programme got underway, the Centre has already reached some significant milestones and is well on cause to achieve its stated objectives.

- Dr Karen Irvine has provided a clear demonstration that remyelination is highly protective to nerve fibres. This work demonstrates the importance of remyelination therapies. Dr Irvine has also shown that nerve fibres that have lost their myelin sheaths are more likely to degenerate as the patient ages.

Dr David Hampton, in collaboration with colleagues from London, has developed a very important animal model of MS which mimics the chronic non-repairing stages of MS that are the key targets for remyelination therapies. This model will be of immense value in testing new remyelination therapies in a way that will enable more secure predications about efficacy in human patients to be made.

- Dr Jeff Huang has recently completed the first phase of a very major project in which he has obtained information on all the many thousands of genes involved in remyelination. This work is highly complex and involves the use of state-of-the-art technology called *microarray profiling*. The objective is to obtain a complete picture of how remyelination works so that we can identify how best to promote it therapeutically. A good analogy is to regard the remyelination picture as being a jigsaw puzzle containing many thousands of pieces. In the past we studied remyelination by taking a handful of the pieces and trying to construct a small part of the overall picture. However, we have never been certain exactly how many pieces of the puzzle there are. As a result of microarray profiling we now know the identity of all the pieces. The challenge now, of course, is to put them all together so we can see what the final picture looks like (remembering that we don't have this picture on the lid of the box!).

- As part of the strategy for understanding how what the remyelination picture looks like Dr Chao Zhao has been developing way in which we can test what newly identified genes are doing. This has involved modifying viruses so that instead of being causing disease they now act as agents for changing the amount of specific genes – either increasing or decreasing their function. This technology will be extremely useful in organising and understanding the information that has been obtained in Dr Huang's work.

- Dr Andrew Jarjour has been developing another system for understanding the remyelination picture. He has been using a technique for putting around nerve fibres (myelination) in a tissue culture dish. This is technically very challenging but enables us to study very specific aspects of this process that are highly relevant to remyelination in a more reductionist and therefore more easily interpreted manner than in the animal models.

The broader picture

The investment that the MS Society has made in the Cambridge Centre has played a very significant role in allowing Cambridge scientists and clinicians to obtain additional relevant research funding. Prof ffrench-Constant heads up a team of scientists from Europe and the USA (and which includes Prof Franklin), funded by the *American MS Society*, that is studying ways to enhance remyelination therapeutically. The work of this team is complementary to and synergistic with the work of the Cambridge Centre. Dr Chandran and Prof Compston has secured significant funding from the *Medical Research Council* to undertake the crucially important task of developing ways in which the efficacy of stem-cell based therapies for remyelination and disease modification can be tested in clinical patients.

DIARY DATES 2006/7

Please do your best to come along. We'd love to see you.

JULY

4th	QUIZ Westfield Court Hotel	7.30-10.00
7th	Collecting Sainsburys Mere Green	All Day
9th	Physiotherapy at Clifton Road Centre	1.00-2.00
16th	Beautician-Jayne Clifton Road Centre	10.00 - 2.00
21st	Awareness Day The Mall	All Day
23rd	Centre Closed for Summer Holidays	

AUGUST

1st	Bingo Westfield Court Hotel	7.30-10.00
3rd	Collecting at Red Rose Centre (Wilkinsons)	All Day
4th	Collecting at Red Rose Centre (Wilkinsons)	All Day

SEPTEMBER

3rd	**CENTRE RE-OPENS**	
3rd	12.30 am until 1.30 pm at Clifton Road	
	Open Forum by Physiotherapists. Come along and find out a little more. A light buffet is available for interested parties.	
5th	Skittles Westfield Court Hotel	7.30-10.00
10th	Physiotherapy at Clifton Road Centre	1.00-2.00
TBC	Beautician-Jayne Clifton Road Centre	10.00 - 2.00
24th	Physiotherapy at Clifton Road Centre	1.00-2.00