

## Successful Open Meeting at Huntingdon

An Open Meeting was held at the Huntingdon, Peterborough and Cambridge (HPC) MS Therapy Centre on 18 October 2009. Representatives from 12 Therapy Centres were joined by all of the MSNTC trustees, staff and National Trainers together with Stewart Long and Stuart Hornsby from the MS Society and Alistair Purser from MIND.

"It is important that we don't lose sight of the bigger picture", said Neil Kemsley, Chairman of MSNTC, as he opened the meeting. "We have been brought together because our lives have been touched by MS". The key to our success is to have a clear vision of why we are here – to help people with and affected by MS, he added.

Organisations need to adapt and change in order to survive and this is especially important in difficult economic times. Recent steps taken by MSNTC to move the organisation forward include:

- Restructuring MSNTC and defining our mission statement and objectives.
- Providing help with matters common to all Therapy Centres (for example oxygen treatment supplies and training, and insurance).
- Helping individual Centres with specific problems.
- Championing best practice in all member Centres.
- Improving the cohesion of the Therapy Centres movement. "I'm pleased to see that we have Centres from as far afield as Cornwall and Cleveland here today in the centre of England", Neil Kemsley remarked.

### Collaboration with the MS Society

MSNTC has also widened the agenda to embrace working together with other organisations for the benefit of all those affected by MS. The two largest societies in the field are the MS Society (with approximately 40,000 members) and the Therapy Centres who are part of MSNTC (with approximately 12,000 members). In October 2009 the MS Society and MSNTC issued a statement affirming their joint wish to work together at national, regional and local levels.

A new project will look at the ways in which a sample number of local MS Therapy Centres and MS Society branches are already working together to improve the quality and range of services available to members of both organisations. It will identify not only the 'success factors' but also those obstacles that have hindered co-operation. The aim is to define a set of criteria which will help Centres and Branches to improve their working relationships and provide more coordinated help for the people that both organisations exist to serve. Stewart Long is responsible for operational delivery for the MS Society in England. He said, "So many of our members are part of both organisations, and I am passionate about looking at areas where they can collaborate. This is a great opportunity for us to learn how to succeed." You can find the full MSNTC/MS Society joint statement on the MSNTC website ([www.msntc.org.uk](http://www.msntc.org.uk)).

### Other Collaborations

A further 10 Centres in Scotland are now more closely linked to the MSNTC movement. Neil Kemsley and David Wray (MSNTC Treasurer) attended the AGM of the Scottish Therapy Centres which took place in Perth on 28 September. A number of areas for future collaboration have been identified and Neil Kemsley said he welcomed the new spirit of co-operation between the two sister organisations.

Alistair Purser, the Regional Services Manager for MIND, formerly managed the MS Therapy Centre in Edinburgh. He is keen to develop relationships between MIND and the MS Therapy Centre in Huntingdon. This is an example of the type of links that can be established locally between charities serving people with neurological illnesses.

### New Database for Centres

Hasit Bakhda gave a presentation on the potential new database for Therapy Centres, and attendees were able to see the demonstration version running during the lunch break. He addressed the numerous questions raised by the Centres in a vigorous email exchange prior to the



*Our hosts were delighted to demonstrate the superb quality of the oxygen chamber they have purchased from Edwin Snowden Ltd to Paul Freeman and Sue Filby*

meeting – these answers are detailed on page 3. The participants at the meeting were won over and concluded that the new system shows potential for providing significant benefits for Centres. Stewart Long was also impressed and said that the MS Society would be keen to work with MSNTC in developing the system to provide information on the treatment of those with MS. This example of the type of co-operation that could benefit all those affected by MS is especially pleasing since in this instance MSNTC is leading the way.

**NEWSFLASH:** since our meeting, the database system has attracted the interest of MS Therapy Centres Scotland, Revive (the MS Therapy Centre in Glasgow), the MS Trust and the MS Research and Relief Fund.

### Other issues

The outcomes of discussions on a number of other issues, including subscriptions, can be found on page 2. Neil Kemsley concluded by thanking all those who had participated in the lively debate both by email and during the Open Meeting, and thanked the HPC MS Therapy Centre for their hospitality.

**The October meeting was well attended and lively**



Glenys Bloomfield

## Meet the Trustees Glenys Bloomfield

In this issue, we profile Glenys Bloomfield, one of the newer MSNTC trustees.

### How long have you been involved with MSNTC?

I became a Trustee in April 2008, after being approached by Vivian Smith.

### What are your special responsibilities within MSNTC?

I am particularly involved in the communications aspects of MSNTC. My role includes writing this newsletter, and helping to set up the new website ([www.msntc.org.uk](http://www.msntc.org.uk)).

### Are you also involved with one of the Therapy Centres?

No, I am not involved with an individual Centre. This means that I don't have the same in-depth knowledge of the Therapy Centres movement as my fellow trustees. On the other hand, it enables me to provide MSNTC with an independent viewpoint – someone like me can bring a fresh perspective.

### What is your background?

I obtained a PhD in endocrinology at Bart's Hospital and I spent a number of years working in biomedical research in the laboratory, including three years in Los Angeles. I then moved into scientific/medical writing and since 1992 I have worked as a freelance medical writer. I work mainly for the pharmaceutical industry although I have also worked for

other medical charities. I've covered a wide range of therapeutic areas including HIV/AIDS, immunological disease, cardiovascular disease and arthritis as well as endocrinology. I've written many different types of publications, from scientific papers to newsletters, patient information leaflets and press releases.

### What are your views on the future of MSNTC and the Therapy Centres?

I've been very impressed by the hard work and dedication shown by all those involved in the MS Therapy Centres. Instead of feeling defeated, they are determined to help themselves and others affected by this disease. I think that communication, both internal and external, is crucial for the future of MS Therapy Centres movement. Internal communication is a two way process between MSNTC and the Therapy Centres. We need to keep each other informed about new developments, problems and opportunities so that we can provide the best possible services to our members. We must also make people in the wider MS community and elsewhere aware of what we are doing via our external communications. I think we should present MSNTC as a professional organisation and emphasise our 'self help' approach, which is our unique selling point. This is particularly important when we are competing for limited sources of funding.

**We need to keep each other informed about new developments, problems and opportunities so that we can provide the best possible services to our members.**

## Open Meeting Issues Q&A

### Membership subscriptions

Subscriptions for full membership will be reduced to £600 pa for 2010. MSNTC had already decided on this in view of the current financial pressures on Centres and recognising that the subscription is a significant element of expenditure for some Centres.

### Rebates for Centres who attend meetings

This initiative was devised in response to earlier suggestions from Centres that the costs of travelling to Open Meetings prevented their attendance. Therefore, to assist Centres with the costs involved in attending meetings in 2009/10, the scheme was announced on page 1 of the summer edition of the newsletter and detailed to those who attended the AGM. The costs of reimbursement will be borne by MSNTC and will not be a "charge" on those Centres who choose not to attend.

### Communications

In response to suggestions that no decisions should be taken unless all Centres were represented at a meeting, and that email might be used as a voting mechanism, it was announced that the planned 'Members Only' section of the website was being introduced shortly. Passwords to obtain access will be sent to Centres so that trustees and staff could access this section of the website.

A members' forum will be set up on the website with the aim of facilitating communication within the Therapy Centre movement – both between MSNTC and Centres and between individual Centres. We hope it will benefit everyone – MSNTC can circulate news/information rapidly and trustees and staff can raise and address their problems, and share ideas on activities e.g. local fundraising, new treatments. In order to gauge opinion, we will

use the website forum to ask for views of member Centres prior to decisions being taken by Trustees which is the only way in which charitable organisations with constitutions like ours can work.

Additionally, this issue of the Newsletter has been given an increased print run so that copies can be more widely distributed both within Centres and externally.

### Fundraising

We recognise that this is difficult in the present economic climate. MSNTC will assist individual Centres with financial problems as far as it is able, as it has done in the past. Specific professional expertise and advice is always available from Vivian Smith, who also can offer places on courses on fundraising including "How to access Grant Making Trusts" run by our patron Roger Jefcoate. The Trustees are also working with Peter Horne to ensure that

the MS Challenge can take place in 2010; and places are being allocated to Centres for the London Marathon in 2010.

### Volunteers

Many Centres have difficulty finding and retaining volunteers and maintaining their enthusiasm. Ideas on how to address this were brainstormed at the open session after the AGM (notes on this have been circulated to Centres) and it was agreed that we should publicise the work of the volunteers who are our 'front-line troops' (see report on Bedford Centre on page 4).

### National Purchasing Power

MSNTC will look into possibilities for bulk purchasing, including items that could be used for fundraising (e.g. badges, pens, key rings etc.). A significant issue is that suppliers need to have large volume orders while Centres may wish to have individually branded items.

# Proposed New Database System for Centres

In the last issue we described the new database system that is being piloted at the Harrow MS Therapy Centre. The Centre is currently using a basic version of the database to manage their membership records and it is now introducing the upgraded version which includes an appointments system that allows the Centre to plan and record treatment sessions.

MSNTC has proposed that this database should be made available to member Centres who wish to use it. Here are the questions that you asked about the database and the answers provided at the Open Meeting.

## What are the costs for individual Therapy Centres?

MSNTC will fund the entire development and set-up costs for the database and will also pay an annual license fee to allow Centres to use the database. MSNTC is confident that they will be able to raise sufficient funds to cover the costs, which are estimated to be approximately £40,000. Vivian Smith has already identified one donor who is willing to provide a significant proportion of the costs.

It is important to point out that this is much less than the costs for installing individual systems at each Centre.

## How secure is the database?

The system will be developed using Oracle, a well established database development tool widely used in many industries, which provides a high level of security. The database will be stored on servers at a secure hosting centre, which can be accessed via a website address. Should anything happen to the hosting company, the database can be moved seamlessly to another hosting service with no interruption in service. No data will be held on a Centre's own server/computer or on those of MSNTC.

## Will MSNTC be able to access confidential patient information?

MSNTC will not control the system or access to the data. No one outside a Centre would have access to individual patient information and the Centres would be able to determine who had access to this within the Centre.

In the long term, the hope is that we could collect data on MS and its treatment that is simply not available at the moment. Initially, MSNTC could collect demographic data such as the number of members per Centre



*Hasit and Malcolm explain the details of the database to Lorraine McGinlay and Mark Boscher from Herts MSTC. Hasit is an IT specialist with an MBA from Cranfield. He is also a trustee of the Harrow MS Centre.*

and the numbers receiving different types of treatments. This would provide important information on the prevalence of MS within the UK, similar to the MS Registry that the MS Society is currently piloting in Scotland. It would also allow us to quantify our services and demonstrate the scope of the help that we provide to people with MS nationwide.

It is hoped that eventually the database will allow Centres to monitor their members' responses to different treatments over time. This would allow us to evaluate the beneficial effects of our treatments both within a Centre and nationally and provide invaluable evidence to support our work. However, only anonymous data would be provided to MSNTC and only if Centres give their consent.

## What new equipment and facilities will Centres need to run the database?

Centres will need computer(s) and internet access in order to use the system. It will be advisable to have broadband as this will be much faster than dial-up access. If the system is a success, Centres might find they need extra computers to make full use of it but it would be possible for people to use their own laptops, for example, since all the data is stored remotely on a host site.

## Who will input the data and can this be done remotely?

It will be up to individual Centres to decide who should input information into the system. The database can be accessed remotely from anywhere with internet access. This means that physiotherapists, for example, could enter data from their own computers. Up to five users per Centre will be able to access the database at any one time, but of course more than five people can be given passwords.

## What about existing appointments and accountancy systems?

The database can be customised for each Centre and Malcolm Anning will visit each Centre and transfer their existing data on an individual basis. The system will have to be tested to check that it can work with accountancy software packages such as Sage and QuickBooks

## What support will be available to help Centres to set up and use the database?

Hasit Bakhda and Malcolm Anning will visit each Centre to assist in setting up the system. As part of the maintenance agreement, they will also be available to provide telephone support Monday to Friday and non-urgent queries will be dealt with via email.

## What are the benefits for Centres?

The aim is that the database system becomes a key part of a Centre's operation, by managing:

- Bookings and appointments
- Treatment records
- Member records
- Staff - holidays, sick leave etc.
- Finances - book-keeping, collecting Gift Aid etc.

Access to a professional management tool will help Centres to run efficiently and optimise their records and finances. Improved appointment systems will help us to present a professional image to our members. It will be possible to assess the profitability and popularity of different types of therapy and ensure that funds such as Gift Aid are collected promptly.

# Dates for your diary 2010

DATE	MEETINGS/EVENTS	LOCATION
February	MSNTC Open Meeting	Wiltshire Therapy Centre For MS Bradbury House Westmead Drive  Swindon
16 May	MSNTC AGM	MK Snap, 20 Bourton Low, Walnut Tree, Milton Keynes, MK7 7DE
26 April – 2 May	MS Week	Various venues nationwide



*MS Challenge - before and after. The top photo shows the team from Hereford Centre preparing to take part in the MS Challenge, held on 4th July, and the one below shows the team from Whitchurch Rugby Club carrying Alison Smithson from the Chester Centre during the event.*



## News from the Centres

The **Solent MS Therapy Centre** in Portsmouth recently celebrated its **25<sup>th</sup> Anniversary** – having refurbished their premises to a high standard, they then set out to party.



The **Bedfordshire and Northamptonshire MS Therapy Centre** recently received the Queen's Award for Voluntary Service, the equivalent of an MBE. The award was presented at the Centre by the Lord Lieutenant of Bedfordshire, Mr. Samuel Whitbread, on 28 July 2009. Valerie Woods, the Centre Manager, said, "We are truly a self-help organisation and we are grateful for this honour to be bestowed on our many volunteers who regularly give their time to help at the Centre in Bedford".

The new building for the **Wiltshire Therapy Centre for MS** in Swindon is due to open in early 2010. The Centre has recently received Heritage Lottery funding worth £220,000 over the next five years. You will be able to inspect the new building when the Centre hosts the first Open Meeting of 2010.

As this is the last edition of the newsletter in 2009 we would like to wish all our readers a Merry Christmas and a successful and eventful New Year in 2010, with lots of stories for us to publish.



A large print copy of this newsletter is available on our website [www.msntc.org.uk](http://www.msntc.org.uk)

Please send your news to: [info@msntc.org.uk](mailto:info@msntc.org.uk)

### MSNTC Contact details

#### Address for Correspondence

PO Box 126  
Whitchurch  
Shropshire SY14 7WL

Tel: 01296 711699  
Email: [info@msntc.org.uk](mailto:info@msntc.org.uk)  
Website: [www.msntc.org.uk](http://www.msntc.org.uk)

#### Patron

Roger Jefcoate CBE

#### MSNTC Trustees

Neil Kemsley (Chairman/Secretary)  
David Wray (Treasurer)  
Paul Freeman (Director O2T Operations)  
Glenys Bloomfield  
Adrian Gilder  
Steven Short

#### MSNTC Consultants

Susan Filby (Accounts)  
Ian Smith (Business Consultant)  
Vivian Smith (Development)