

Annual Review 2010

Multiple
Sclerosis
Trust

MS





68,000

books and factsheets were sent out last year



15%

increase in the number of enquiries we received



745

nurses and therapists attended our professional educational courses



Welcome...



The Multiple Sclerosis (MS) Trust is a small organisation, so whenever we embark on a new project, we ask ourselves “will this help people with MS?” and we only proceed if we are sure it will and that we are best placed to deliver it.

In this annual review, we asked the people that really matter, those who live and work with MS, how our work helps them. I would like to thank everyone involved for giving up their time and agreeing to be photographed. Their honesty and willingness to share their experiences conveys the essence of the MS Trust; that everything we do is about improving life for people with multiple sclerosis.

Living with a lifelong, incurable condition like MS is challenging, and the world around us at present seems determined to make things even more difficult. We are hearing from people affected by MS that their jobs are under threat, benefits are being reassessed and cut back and we are all concerned about the security of the MS specialist services that can make such a difference.

Our own income has also been hit by the recession and with limited resources it is even more important for us to focus on what people tell us is essential. With reduced resources, the team have continued to deliver new publications and the most up-to-date information on MS and to offer essential and unique educational courses for health professionals working with people with MS. We have developed practical tools to help specialists defend their posts and have campaigned for the MS nurses both locally and nationally to ensure we do not lose specialist services and we have continued to fund research projects that can lead to improvements in the lives of people living with MS right now.

2011 looks like being an equally challenging year for us all, but we are committed to ensuring everyone affected by MS has access to the health information and specialist services they need to make the right decisions for themselves.

Thank you to all of you, who have inspired, informed and supported our work.

Pam Macfarlane
Chief Executive

“Whenever we embark on a new project, we ask ourselves will this help people with MS?”

Key facts about Multiple Sclerosis

- There are 100,000 people with MS in the UK and 2.5m in the world
- 50 people a week are diagnosed with MS
- People with MS are often diagnosed in their 20's and 30's
- Three times as many women have MS
- MS is the most common cause of disability in young adults
- Only 1 in 4 people with MS regularly use a wheelchair

MS Trust's Key Achievements in 2010

In response to the needs of people with MS we produced new information books and factsheets including:

- MS and me – a self management guide to living with MS
- Talking with kids about MS
- Vitamin D; Depression; Clinically isolated syndrome

We held two online chatrooms on fatigue and spasticity so that people had the opportunity to ask an MS expert questions.

Realising that more people affected by MS are using the internet, we launched our interactive exercise programmes on the website.

Following a long campaign by the MS Trust and others, the cannabis-based mouth spray, Sativex, was licensed as an add-on treatment for MS related spasticity.

Our Kids guide to MS for 6-10 year olds and our website Staying Smart, which helps with memory and cognition, were commended at the British Medical Association Patient Information Awards.

To make it easier for people affected by MS to contact us, we launched a new freephone number for our information service, 0800 032 3839.

We had a 15% increase in the number of enquiries we received and sent out over 68,000 information books and factsheets last year.

The MS Trust was invited to be a judge on the Real MS Voices international film competition.

We funded practical research projects in fatigue management and core stability.

We continued to support health professionals to improve services for people with MS.

745 nurses and therapists attended our professional educational courses which included:

- Four regional study days covering topics including depression, bladder and bowel management, and spasticity
- Two Therapists in MS (TiMS) study days held in London and Glasgow
- Two week-long Development Modules for MS specialist nurses and therapists new in post
- An annual two-day meeting for MS specialist nurses
- An annual multidisciplinary conference

On average, 900 people use the MS Trust's website each day

Supporting people with MS



I was diagnosed with relapsing remitting MS on the 25th April 2008. I had previously visited my GP who thought I had an ear problem because of the balance problems I was experiencing. I could not walk and had to have my boyfriend or friends with me all the time. I also had blurred vision and my speech was very slow.

I ended up in A&E and had a CT scan. I was given antibiotics because they thought I had a brain infection. I then had an MRI and was told that I had MS. I was very upset but just glad it wasn't a brain tumour. My boyfriend, now fiancé, was a great support at the time.

My mum, who lives in the Czech Republic, was devastated. She thought that was it for me and imagined me in a wheelchair. She also felt guilty as she thought it was her fault. We talk every week and I pass the MS Trust's information onto her which has really helped her to understand more.

I contacted the MS Trust because I was off sick for nine months due to a major relapse in August 2008. Every day I went on their website reading information which I hadn't received from anyone else. I did the Santa run in 2009 to say thank you to the MS Trust.

Friends told me my nursing career was over. However, I now work on the neurology ward and work with many MS patients who I share the MS Trust's information with. For me, working with MS patients is a privilege because I want to help others to think positively and show that life can carry on.

Zuzana Neumannova (aged 29)



"My mum contacted the MS Trust's enquiry service when I first had optic neuritis and also when I had a breakdown. As well as the information she received, being able to speak to someone was a great comfort and support. There is too much information on the internet so it's reassuring to have the MS Trust's website which I know I can trust."

Sarah Djavit (aged 38)

Every new MS specialist nurse attends the MS Trust's week-long Development Module



Working with health professionals



I have been an MS nurse for 12 years and have worked with people affected by MS for 17 years. I first came across the MS Trust when I attended their educational conference in 1998. I was impressed by their professionalism and drive to produce information for health professionals and improve outcomes for people with MS.

The MS Trust helps me to do my job by providing information that is always up-to-date and by reporting on the latest research in an unbiased way. The website is easy to navigate, and their factsheets are particularly useful. Unfortunately, newspaper headlines often get people's hopes up and I then have to tell them the reality. It's essential that I can direct patients to a trusted source which follows on from what I have already advised. The MS Trust is a good balance of fact and hope.

Pauline

I have been an MS nurse since April 2009. I was a district nurse for 15 years prior to that. During this time I had unfortunately seen a very negative side of MS. It was when I became a case manager that I saw that if people with MS received the right help and information their outcome could be better.

In 2007 as a case manager, I needed information about MS and that's when I first found the MS Trust's website. It was invaluable at this time. When I became an MS nurse I attended the MS Trust's Development Module which provided me with good foundation knowledge of MS and helped to build my confidence early on. Since then, they have provided me with ongoing information, education and support.

The MS Trust provides unique education to MS nurses and therapists which they otherwise wouldn't receive. All of their events have a common goal; to share information and help people with MS.

Suki

*MS Nurses, Pauline Shaw and Suki Flora,
Dulwich Community Hospital*



"I am now seeing an MS nurse on a regular basis and this gives me a lot of support and help in managing my MS. I think it's essential that MS health professionals continue to receive education and support from the MS Trust. MS news and research is changing all the time so it's important that they're kept up to date."

Graham Griffiths (aged 62)

Our information books for
parents and children helped over
5,000 families living with MS



Supporting families affected by MS



I was diagnosed in December 1990 aged 25. I thought I wouldn't end up getting married or having children and that I'd end up being a burden to everyone. I didn't receive any information when I was given my diagnosis.

The only information or support groups I could find at the time were quite negative and talked a lot about disability. I then came across the MS Trust and was pleased to read their clear and positive information, which felt so different.

When I met my husband I'd had a lot of left side problems; my leg used to drag and I'd fall over a lot when I got tired. I didn't know how to explain it to him. I did tell him after a while and I got some information from the MS Trust for him to read. Deciding to have children was a big decision for me because when I was diagnosed I was told that I could never have children. This is another time when I needed lots of information.

Bethany used to ask lots of questions including 'will you die mummy?' but my son James didn't really want to know. I really needed something which I could give to them to read. That's when I came across the MS Trust's book for children. They kept it on their bookshelves and I know they still read it. More recently I was given the MS Trust's Young Persons Guide to MS which was really helpful for James because as he got older, he wanted more detailed information.

I also really appreciate the support I get from my neurologist. I can just ring him when I have a relapse and he sees me straight away.

Lynda Davis (aged 47) and daughter Bethany (aged 10)



"The MS Trust consistently produces high quality information for people with MS and healthcare professionals. I often recommend their website and excellent publications covering topics such as treatments, exercise and relationships to my patients."

The MS Trust's annual conference is an energetic and positive event which encourages multi-disciplinary learning to benefit people with MS."

*Dr Eli Silber,
Consultant Neurologist*

£275,000 was raised for the MS Trust by people taking part in running events in 2010



Helping the MS Trust to help others



I was diagnosed with MS in 2003 following a severe tightness in my left leg which left me unable to walk. I had an MRI scan and lumbar puncture which confirmed my diagnosis. I had physiotherapy whilst in hospital which really helped my leg. Looking back I had experienced nerve problems in my hand in 1999 which I now know were symptoms of MS.

In 2005, I contacted the MS Trust for information after my MS nurse told me about them. I particularly like the MS Trust's website because I trust it. There's too much information out there on the internet which can be very frightening. My MS nurse also gave me some MS Trust books explaining MS which I passed on to my employer. As a result, I've been able to change roles at work to accommodate my fatigue.

My brother, my MS nurse and the MS Trust have been a great support.

Nerys Adu-Bonsra (aged 36)

When my sister was diagnosed with MS I wanted to do something proactive to support her and so decided to raise money for the MS Trust by taking part in a 10k run. I started joining my sister and her friend at the park every Sunday, although I only managed one lap the first time! Since then, I have gone on to do half marathons and last year did my first full marathon. It was hard but knowing I'm supporting my sister and the MS Trust helps me carry on past the pain barriers, so much so that I have signed up to do the 2011 London Marathon for the MS Trust! I find sponsors are so generous because they understand my connection with the cause. There couldn't be a bigger motivation than knowing I'm supporting my sister!

Hywel Adu-Bonsra (aged 35)



"It is vital that I am able to direct people to trusted information. The information the MS Trust provides is readily available and easy to access which would be very difficult to replicate in the NHS."

Suki Flora, MS Nurse

Research and Campaigning

Funding practical research

“The MS Trust Research Programme is invaluable in funding research which explores aspects of management and care that have immediate relevance to the daily lives of people with MS. From a researchers perspective, this provides the opportunity to undertake smaller scale developmental projects; which is an essential platform for moving on to submit bids with larger funding bodies. Crucially the MS Trust does this in a supportive and acilitativem anner.”

*Dr Jenny Freeman,
Associate Professor
(Reader) in Physiotherapy,
University of Plymouth.*



Campaigning for better MS services

In 30 years caring for people with MS I have seen how the MS Trust’s campaigning has dramatically helped to increase the number of specialist nurses from just 3 in 1995 to over 200 now. However, changes within the NHS and loss of funding has resulted in MS nurse posts becoming increasingly under threat and MS nurses look to the MS Trust to help protect and defend the care people with MS so badly need.

At the MS Trust, we are gathering robust evidence and resources that will protect and justify the MS specialist nurse now, and in years to come. With our support, six nurses whose posts were under threat this year have managed to keep their services safe. This means specialist services have been saved for around 3,000 people with MS.

In my role at the MS Trust I work closely with MS nurses to prove their value to others; particularly those who do not understand the complex needs of people with MS. I lobby government and national nursing bodies on behalf of MS specialist nurses and their patients. There is still much to be done to ensure people with MS have access to the very best care and support.

Vicki Matthews (pictured on the right above) is the MS Trust’s MS Specialist Nurse Advisor. Vicki is also a committee member of the Royal College of Nursing’s Neuroscience Committee and MS nurse in Southampton’s Neurosciences Centre.

Thank you

We would like to thank the following charitable trusts and foundations in particular for their support in 2010.

Albert Hunt Trust
Bernard Sunley Charitable Foundation
Bothwell Charitable Trust
Champneys Charitable Foundation
Drapers’ Company
Dunn Family Charitable Trust
Ernest Kleinwort Charitable Trust
Helene Sebba Charitable Trust
Henry Smith Charity
John Harrison Charitable Trust
Kirby Laing Foundation
MacRobert Trust
Monica Rabagliati Charitable Trust
N Smith Charitable Settlement
South Square Trust

We would like to say a special thank you to the following people for their significant support during the last year.

Edith Conn OBE	Alison Shaw
Rick Halsall	Kenny Smith
Jill Holt and Stuart Martin	David Rutter
Mike Laver	Karen Williams
Jonathan Pierce	

Finally, we would also like to thank everyone who has supported us by:

- Raising awareness of MS and the MS Trust’s work
- Telling others about our services
- Telling us what people with MS need
- Completing our surveys
- Buying or selling our Christmas cards
- Making a donation
- Gift aiding their donations
- Responding to appeals
- Giving regularly
- Donating in memory
- Remembering us in their will
- Sharing their story
- Volunteering
- Fundraising for us
- Joining us on Facebook and Twitter
- Contributing to our publications and website



“We would like to say a big thank you to everyone who has supported us during 2010. We could not continue our work without you.”

MS Trust

Facts and Figures

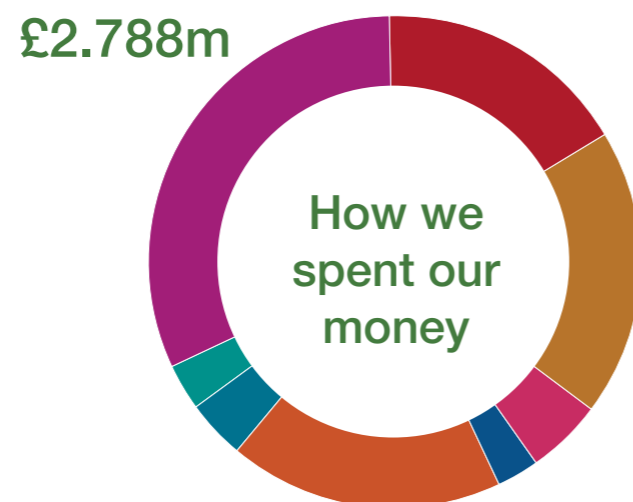
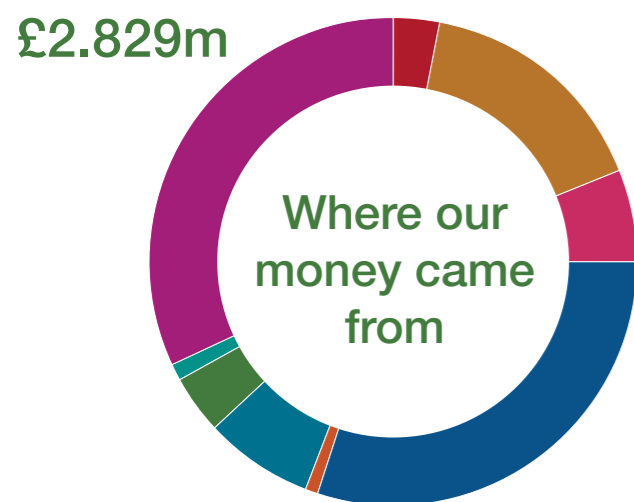
For year ending 31st July 2010

The MS Trust works hard to ensure the money it receives from generous individuals, trusts, foundations and companies is used effectively and efficiently to fund our projects and services which support people with and affected by MS.

Thank you to all who have been able to support our work over the last year. You have made it possible for us to directly help over 37,000 people across the UK, as well as provide health professionals with the resources they need to help everyone affected by MS.

We are pleased to present here a summary of the MS Trust's audited accounts.

If you would prefer to see the full version of the accounts, they can be downloaded from our website, www.mstrust.org.uk/accounts or you can request a copy from us by calling 01462 476700 or by emailing info@mstrust.org.uk



- | | | | |
|------------------------------|------------------------------|------------------------------|------------------------------|
| ■ Grants 3% | ■ Legacies 7% | ■ Information 17% | ■ Fundraising 18% |
| ■ Professional Education 16% | ■ Trusts 4% | ■ Professional Education 18% | ■ Christmas Cards 4% |
| ■ Christmas Cards 6% | ■ Investments 1% | ■ Grants for Research 5% | ■ Governance 3% |
| ■ Donations 30% | ■ DH Risk-sharing Scheme 32% | ■ Policy and Campaigning 3% | ■ DH Risk-sharing Scheme 32% |
| ■ Companies 1% | | | |

The full accounts of the MS Trust have been audited and given an unqualified opinion. The full accounts were approved by the Trustees on 9 December 2010 and were submitted to the Charity Commission and the Registrar of Companies.

Note on the Department of Health Risk-sharing Scheme (RSS)

The RSS is a 10-year (minimum) research project to assess the cost efficacy of disease modifying therapies for people with multiple sclerosis. The research project is funded equally by the Department of Health and four pharmaceutical companies Biogen Idec Ltd, Bayer Schering Pharma UK Ltd, Merck Serono Ltd, Teva UK Ltd & Sanofi Aventis Ltd. The project is carried out by an external clinical research organisation Parexel, together with clinicians from the Universities of Liverpool and Oxford. The MS Trust's role is to act as administrator, which involves ensuring work is completed and paid for in line with the contracts, and the funders are invoiced for their share, as well as providing support to the independent scientific advisory group. This resulted in a 2010 income stream for the MS Trust of £900,837 which is exactly matched by external payments to the research organisations.

The Year Ahead

People with MS – you and me, our families, our friends, our health professionals; the MS Trust is working with us and for us, and what they do is top quality! The Trust may be small in size but it is hugely respected within the health professions community and that helps us as patients.

I've had MS for 30 years now. The MS Trust didn't exist when I was first diagnosed but since its start in 1993, it's proved its worth. The excellent books and the personal information service provide us with the facts and support that we need to help us to continue to make our personal contribution to society in whichever way we choose to do.

The MS Trust is meeting the challenges ahead – the growing need for information on topics such as staying in work, the continuing advances in the Disease Modifying Therapies available to us, a reformed NHS, the threat to MS specialist nurse posts – to name just a few. I know just how valuable my MS nurse is to me when I hit a really bad patch; she's a key link to getting the professional input I need.

The MS Trust needs our help too. We can tell people about our MS Trust and its plans for the future. Support comes in all forms, not just financial. I support the Trust as an active Patron and fundraiser as I strongly believe how important it is to keep MS at the front of people's minds.

Sarah Joiner,
Patron, MS Trust



"Please keep up to date with what we are doing by visiting our website at www.mstrust.org.uk. If you have any thoughts you'd like to share with us, do please let us know."

Key facts about the MS Trust

- The MS Trust was established in 1993
- 28 staff provide all of the MS Trust's services
- The MS Trust has one office which is based in Letchworth, Hertfordshire
- The original co-founders of the MS Trust are still Trustees today
- The MS Trust conducts the only national survey of MS services in partnership with the Royal College of Physicians
- The MS Trust is in contact with 37,000 people living and working with MS

MS Trust Patrons

Laurence and Jackie Llewelyn-Bowen
Lady Rifkind
The Hon Sarah Joiner

MS Trust Trustees

Mr Russell Hardy (Chair of Trustees and founding Trustee)
Professor Mike Barnes (Professor of Neurological Rehabilitation at the University of Newcastle)
Mr Nick Kavanagh (Lecturer in Charity Finance and Finance Officer of the Arvon Foundation)
Dr Dawn Langdon (Reader in Neuropsychology at Royal Holloway, University of London)
Dr Alexander Burnfield (Retired Consultant in Child and Family Psychiatry)
Ms Jill Holt (Founding Trustee)
Professor Neil Scolding (Burden Professor of Clinical Neurosciences and Director of the Institute at Frenchay Hospital)
Ms Helen Caulfield (Head of Legal at the Human Tissue Authority)
Ms Thea Longley (a Partner with Bates, Wells & Braithwaite)
Mrs Christine Jones (Founding Trustee)
Mr Paul Budd (External Relations Director, Royal Mail)
Wing Commander Mike Laver RAF(Retd)

Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T 01462 476700
E info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353

Photography by Ed Miller www.edmiller.co.uk

