

Research Matters

The latest developments, innovations and achievements in MS research

Our project to find your top 10 research priorities

Page 6

Read the results and our plans to tackle them

Page 8

Research Priority edition

Where should research go next?

Participant perspective

"It was great hearing other people's opinions but also to have my voice heard"
Hear from people involved in the project. [Page 20](#)

PLUS The latest MS Society research news, projects and announcements



MS

Multiple Sclerosis Society

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Welcome to Research Matters

I am delighted to welcome you to this special edition of Research Matters. We are pleased to share the results of our MS research priority setting partnership, which set out to find the top 10 research priorities most important to you and to health care professionals.

Here at the MS Society we believe that people affected by MS should be at the heart of MS research. You can read about the experiences of three people who took part in the project on pages 20-21.

Pages 6-19 are dedicated to the results of the project to set MS research priorities. Read all about the process we went through, what made the top 10 and what our plans are to tackle these research priorities.

We also funded 18 exciting new research projects in 2013, spending a total of £2.1 million on new research. We committed to supporting projects from improving mobility to discovering potential myelin repair therapies and understanding cognitive difficulties in MS (pages 4-5).

And finally, turn to pages 22-23 to find out about MS Life 2014. Join over 3,000 people in Manchester at the biggest event in our calendar. You'll experience everything from listening to research talks and enjoying cookery demonstrations, to getting a massage and much more.

I do hope you enjoy this issue. If you'd like to get more MS research news and comment, remember to check out our website www.mssociety.org.uk/research and research blog.

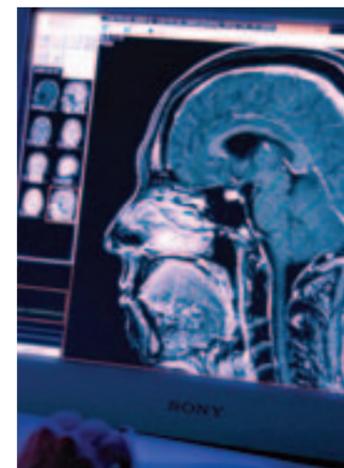
Finally, I would like to sincerely thank everyone who got involved in the priority setting project – it really was a group effort. I am very proud of what we achieved and its potential to shape what MS research is funded in the future.

Nick Rijke

Nick Rijke
Interim Director of Policy
and Research



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Research Matters is available as an audio download. For details telephone **020 8438 0999**

Latest MS research

Autumn last year saw the MS Society announce funding for 18 groundbreaking research projects, taking spending on new research in 2013 to £2.1 million. Here we focus on just a few of them.

Improving Mobility in MS

UNDERSTANDING MORE ABOUT CHRONIC LEG SWELLING

Dr Vaughan Keeley | £108,622 | 1.5 years |

Derby Hospitals NHS Foundation Trust

People with MS who have limited mobility can develop painful chronic leg swelling, leading to infections requiring hospital treatment. This project aims to find out how many people with MS experience leg swelling and the impact it has on their lives. This could help to improve management through better detection, and development of more effective treatments.

Find out more
about mobility
on page 17

Developing a falls management intervention

Dr Jenny Freeman | £15,388 | 1 year |
University of Plymouth

People with MS can be at greater risk of falling due to balance and mobility problems. This project will review the scientific evidence around falls management, taking into account the views of people affected by MS and health professionals. Researchers will then design a falls management intervention specifically for people with MS.



Preventing disability progression

Are systemic infections linked to progression in MS?

Dr Ian Galea | £256,023 | 3 years |
University of Southampton

There is some evidence that systemic infections (such as colds and chest infections) are linked to a more rapid accumulation of disability in people with MS.

Researchers will record the number of infections people with MS have and their response to each infection. They will also study the progression of MS using MRI scans and a series of clinical exams and questions. Once they find whether infections can cause or contribute to disability accumulation in MS, they may be able to develop treatments that could slow, or even prevent, disability accumulation and progression.

FINDING NEW REMYELINATION TARGETS

Dr Julia Edgar | £30,802 | 1 year |
University of Glasgow

Researchers will work with the Scottish Bioscreening Facility to develop a technique called a 'high-throughput screen' to look at thousands of different molecules that may have the potential to repair myelin. If successful, researchers will be able to take the most promising molecules into early stage testing and, eventually, clinical trials in people with MS.

Read what else
we're doing about
progression
on pages 8-11

Memory and thinking

Many people with MS experience problems with cognitive processes such as memory, decision making and concentration. Unfortunately, there are few effective treatments for these symptoms, and no reliable way to measure someone's responses to treatments in a clinical trial. These two new projects using imaging techniques aim to address this.

Functional MRI (fMRI) and Graph Theory

Dr Robert Dineen | £95,794 |
3 years | **University of Nottingham**

fMRI is an imaging technique that measures blood flow in the brain to try to understand brain activity. The researchers will analyse fMRI data, using a technique called Graph Theory, to measure and describe the organisation of networks in the brain.

Hopefully this will reveal specific differences in the brains of people with MS with cognitive difficulties, which could be used to measure the effectiveness of new treatments. The researchers will test these measures in a small trial of an intervention designed to improve cognition in people with MS.

Read more
about cognition
on page 18

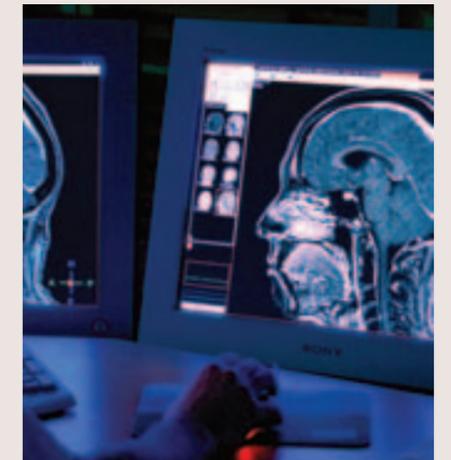
MAGNETOENCEPHALOGRAPHY (MEG)

Dr Nikos Evangelou | £39,232 | 7 months |
University of Nottingham

MEG uses scalp detectors to measure electrical activity in the brain. It is a rapidly improving technique, allowing us to observe brain activity at very high resolutions and over very short timescales.

The researchers will use MEG to compare people with and without MS, to understand the cognitive changes occurring in people with MS. They will then use a powerful MRI scanner to understand how these changes in brain activity detected by MEG are linked with changes in brain structure seen using an MRI scanner.

This could lead to better ways of measuring changes in cognition, aiding the development and testing of future treatments for this symptom.



Want to find out more?

For the latest on MS Society funded research visit www.mssociety.org.uk/research or call the Helpline on 0808 800 8000 (weekdays 9am–9pm)

You can help us beat MS

Your support is vital if we are to continue funding research projects like these. Visit www.mssociety.org.uk/donate or call 0800 100 133 to make a donation.



Finding the top 10 research priorities

To find out more
about the project visit
www.mssociety.org.uk/jla

In 2012 we began a project to find the 10 unanswered questions in MS research that are most important to people affected by MS and health care professionals. Here's what we did.

WE'VE COME a long way since 1956, investing over £148 million (in today's money) in MS research. This has advanced our understanding of MS, improved diagnosis and supported development of treatments. These include early trials of Botox for bladder problems, and alemtuzumab, which has recently been licensed as a treatment for relapsing remitting MS.

To ensure our work continues to reflect the needs and wishes of people affected by MS, we set up a 'James Lind Alliance MS priority setting partnership' to find out what research questions really matter to people affected by MS and the health care professionals who treat them.

Nick Rijke, Interim Director of Policy and Research at the MS Society explains: "The field of MS research is vast, as is the number of potential projects that could be



JLA workshop participants

"We feel it is crucial that people with MS and those who treat and care for them are at the heart of everything we do."

funded. For our research to continue to have life-changing impact, we need to prioritise research questions and our resources.

He continued: "We feel it is crucial that people with MS and those who treat and care for them

are at the heart of everything we do".

Often researchers and funders play the dominant role in the development of research strategies, and the priorities and voices of people affected by health conditions struggle to be heard.

THE PROCESS



Question gathering

The steering group oversaw a large survey collecting questions from anyone interested in MS
507 people submitted 1084 questions

Sorting

Questions were grouped into topic areas and duplicates combined. Current evidence was reviewed and unanswered questions went forward for prioritisation
67 questions went forward

Prioritising

People affected by MS and health care professionals voted for the questions most important to them
669 people voted

Narrowing down to 10

The top 30 questions were discussed in a workshop (35 people affected by MS and health care professionals). Different views and perspectives were heard and people thought broadly about MS.
Top 10 selected!

Turning top 10 into research

The top 10 will complement our research strategy and hopefully influence researchers and the other funders to take on new or different projects

Introducing Sally Crowe



Sally has been a JLA Adviser since 2005 and worked with 16 partnerships, she was selected as the chair for the MS partnership. We spoke to her about her experience.

"My role as the chair was to facilitate the process, encourage and support everyone involved to ensure the results reflected the research priorities that people affected by MS and health care professionals value most. It's vital these are highlighted so they can be addressed by the research community.

"Engagement was key to the process and was built on our principals of being inclusive, transparent and accountable. I was completely overwhelmed by the commitment, passion and enthusiasm of the MS community.

"I was also delighted to see the building of lasting partnerships between researchers, people affected by MS, health care professionals and funders.

"Sadly my work's now over; I really enjoyed working on the partnership and look forward to seeing the fruits of our labour – newly funded research."

Chris McNamara, who has MS and took part in the project, told us: "It is absolutely vital to know the difference between what's interesting and what's important. I have my own list of priorities and if I don't shout about it, no one will."

"It's absolutely vital to know the difference between what's interesting and what's important."

Q&A

What is the James Lind Alliance (JLA)?

The JLA is an independent, internationally recognised, non-profit organisation with an established transparent process of bringing together people with health conditions, carers and health care professionals to identify and prioritise research, whilst taking into account existing evidence. They've worked with a wide range of partnerships including prostate cancer, type 1 diabetes, schizophrenia, dementia and stroke.

What are priority setting partnerships?

These are groups of people – those with a particular health condition and organisations representing them, together with carers and health care professionals – who work together to identify and prioritise unanswered research questions.

Who was involved in the MS partnership?

The partnership was overseen by a steering group made up of the JLA, the MS Society, the Association of British Neurologists, the UK MS Specialist Nurse Association, the MS National Therapy Centres, health professionals and people with MS from the MS Society's Research Network.

Who was James Lind?

The JLA take their name from James Lind, an 18th century Scottish naval physician, credited with carrying out the first clinical trial in the history of medicine, from which he developed the theory that citrus fruits cured scurvy.

The results

After 18 months of surveying, prioritising, discussing and ranking, we now have the top 10 research priorities agreed by people affected by MS and health care professionals. Here we look at them in detail and discuss how we'll tackle them.

1 "Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?"

Currently, there are a lack of treatments that can slow, stop or reverse the accumulation of disability that people with progressive MS experience. We need to change this.

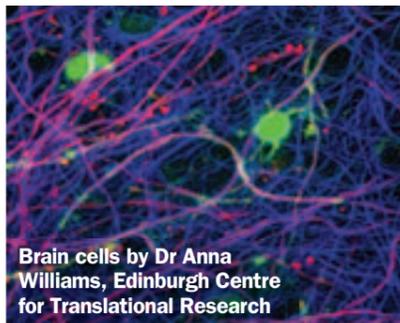
WHAT WE KNOW ABOUT PROGRESSION

Our understanding of how disability progression in MS happens has greatly improved over the years. Researchers are doing more and more progressive MS research – there's now real momentum. Dr Raj Kapoor, consultant neurologist and MS researcher, explains: "People with MS can accumulate disability over time. This can be caused by relapses, or by some of the processes which cause progression. In both situations, myelin can fail to repair itself after damage by the immune system, or the nerve cells themselves can degenerate. "In MS, immune cells cross the blood-brain barrier. Once these immune cells get into the brain or spinal cord they can then

Why do we have myelin?

Myelin has two functions. One is conductivity – it helps messages travel around the body quickly and accurately. During relapses, myelin becomes damaged by the immune system causing the distorting of the signals travelling around the body.

Myelin's second function is protection. It physically protects the underlying nerve fibre. The brain does have some natural ability to repair myelin, but as we age, and if it is attacked continually, the myelin loses its ability to re-grow. When this happens the nerve fibre underneath is no longer protected and can be damaged.



Brain cells by Dr Anna Williams, Edinburgh Centre for Translational Research

mistakenly attack myelin, the fatty insulating substance that coats nerve fibres.

"When the nerve fibre itself becomes damaged or broken, permanent accumulation of disability can happen.

Unfortunately, there's nothing currently available that can repair damaged nerve fibres."

WHAT WE'RE DOING ABOUT PROGRESSION

Developing treatments for progression has been a key focus of our research programme over the past five years. We have also highlighted it as one of the top biomedical priorities in our Research Strategy, which will run from 2013-2017.

International interest in progressive MS research has also increased over the last

few years, largely stimulated by the Progressive MS Alliance (PMSA; previously known as the International Progressive MS Collaborative).

The PMSA was co-founded by the MS Societies in the UK, USA, Canada, Italy and the Netherlands. It's developed a list of shared progressive MS research priorities and has just launched a call for research applications with funding decisions to be made soon. We'll continue our involvement in the PMSA to promote and fund progression research on an international scale.

MYELIN REPAIR

In 2005 we set up the Cambridge Centre for Myelin Repair and in 2007, with support from the Volant Trust, the Edinburgh Centre for Translational Research.

Researchers from these centres are working together to study how myelin repair happens naturally, and to develop new therapies that can target these natural mechanisms in people with MS. They are trying to translate these laboratory findings into clinical trials as quickly as possible as well as working to discover new potential myelin repair targets that could be used as a basis for clinical trials.

They are making breakthroughs. In 2011, researchers led by the Cambridge centre in collaboration with the Edinburgh centre, discovered that targeting a molecule called 'RXR-gamma' in laboratory models of MS, could stimulate the brain's own stem cells to repair damaged myelin.



Researchers are doing more and more progressive MS research – there's now real momentum.

We have committed a further £2.1 million to the Cambridge centre so they can continue their vital work. Part of this funding will go towards a small clinical trial of a drug that targets RXR-gamma in people with MS that will be run by both centres.

Professor Robin Franklin who leads the Cambridge centre explained more: "If a treatment was developed that could restore lost myelin, this could potentially slow or stop the progression of MS.

"If lost myelin is repaired and if immune attacks were stopped too (via current disease modifying drugs) then there's the possibility that in addition to stopping progression, the brain's adaptive mechanism may even allow some reversal in disability progression."

Although small trials will start soon, he pointed out that we are still in the early stages of moving laboratory developments into the clinic and it may be 10-15 years before truly effective myelin repair therapies are developed. "Our hope and expectation is that this could

really change things for people with MS and give people hope for the future."

In 2013, researchers led by the Edinburgh centre in collaboration with the Cambridge centre discovered that a protein inside cells, known as 'activin-A', could potentially be targeted as a way to repair damaged myelin. Researchers will now look to find treatments that stimulate activin-A, to encourage repair of myelin in the brain.

75%
of research projects we are currently funding are addressing the top 10 research priorities

NEUROPROTECTION CLINICAL TRIALS

Neuroprotective strategies are treatments that have the potential to protect nerve cells from damage. This could potentially slow or even halt the progression of MS.

We announced in 2013 that we are co-funding a groundbreaking phase 2 clinical trial named MS-SMART, which will test three drugs against a placebo in 440 people with secondary progressive MS. The drugs have shown potential to protect nerves from damage in very small studies in people with MS.

This trial, led by Dr Jeremy Chataway at University College London (UCL) and Professor Siddharthan Chandran at the University of Edinburgh, was developed by our UK MS Clinical Trials Network. We're also currently funding two other phase 2 trials looking at

Protecting nerves from damage could potentially slow or even halt the progression of MS.

the safety and effectiveness of amiloride (carried out at the University of Oxford, led by Dr Matt Craner) and phenytoin (led by Dr Raj Kapoor at UCL) in people with optic neuritis to see if they can protect the optic nerve from damage. If these drugs could protect the optic nerve



from damage, then they could potentially protect all nerves and hopefully slow or stop progression.

STEM CELLS

Stem cells are of great interest as a therapy for MS due to their ability to potentially repair or replace damaged tissue. The current potential of stem cells are as neuroprotective or immune-modifying treatments – to prevent damage to the nerves or by repairing damaged myelin which could slow or stop disability progression.

We created a partnership with the UK Stem Cell Foundation to invest in MS stem cell research. It has funded amongst other projects, part of a phase 2 clinical trial of adult mesenchymal stem cells that have shown potential to be neuroprotective.

WHY IS THIS SO IMPORTANT?

Roger Bastow, who has primary progressive MS explains: "Researching progression is a complex business and progress can appear slow. As with many things in life, research takes time – unfortunately there's no quick route. However, I believe that with the level of investment and interest in the subject increasing all the time, we are making progress.

"I really believe that research is the only way forward and I hope that MS can one-day be ended for future generations. This is what

helps to keep me going."

Rachel Wallbank, an occupational therapist who took part in the final workshop told us that she thinks "this result will help researchers to focus more on progressive MS."

She continued: "This brings new drive to tackle the issues and gives hope to people with progressive MS that something is being done."

MS Society's Clinical Trials Network

In 2007 we set up the UK MS Clinical Trials Network, made up of leading neurologists, scientists and experts in clinical trial design, who were tasked with developing a phase 2 clinical trial for progressive MS.

The group commissioned and carried out four projects costing around £500,000 needed to help inform the design of the MS-SMART trial and secure funding from the government.

They're now widening their scope to support clinical trials in the UK for both progression and symptom management.

2 "How can MS be prevented?"

Preventing people from developing MS in the first place is the ultimate goal for the MS research community.

Advances in MS research over the last 10-20 years have given us a better understanding of the potential causes of, and risk factors for, developing MS.

The most studied risk factors for MS to date include: genes (110 have been linked with MS), vitamin D deficiency, exposure to Epstein Barr Virus and smoking.

Despite this, little is understood about how these risk factors

interact to influence the development of MS – and designing experiments to better understand this is not straightforward.

Dr Susan Kohlhaas, Head of Biomedical Research at the MS Society explained: "Developing and conducting definitive prevention clinical trials may take decades and cost tens of millions of pounds. So any prevention strategies that are developed and tested must be thought through and based on good underpinning evidence."

"Prevention is very important to me because, as a father, I don't want my children to be at risk of developing MS."



What is MS-SMART?

It's a first in MS research. It will test the safety and effectiveness of three different drugs against a placebo. This is quicker and cheaper than running three individual trials.

The three drugs are licensed for other conditions – amiloride (blood pressure and heart disease), ibudilast (asthma) and riluzole (motor neurone disease), so we already know about the safety profile of these drugs. This speeds up the development process.

Edinburgh Clinical Trials Unit will look after the day-to-day running of the trial and scientists at UCL will manage the MRI analysis. It's co-funded with the Medical Research Council's 'Efficacy and Mechanism Evaluation Programme', with additional support from MS Societies in the USA and Italy.

For more information on the trial go to www.ms-smart.org

WANT TO FIND OUT MORE ABOUT RISK FACTORS?

Read the Summer 2013 issue of Research Matters. For a copy, call **020 8438 0999** (weekdays 9am-4pm) or visit www.mssociety.org.uk

OUR STRATEGY

We plan to run an international workshop to identify the background research needed to further understand prevention of MS.

The workshop could identify:

- ▀ which risk factors could be used to develop prevention strategies
- ▀ the feasibility of long-term prevention trials
- ▀ the design of long-term prevention trials
- ▀ what research needs to be done to address this priority

We will also continue to highlight research into causes of MS as well as potential prevention to researchers applying for funding.

INVESTMENT IN GENETICS

We're proud of our investment into genetics research. We now know there are around 110 genes linked with MS and we're pleased to have co-funded many of the studies that discovered those genes.

These genes provide clues to the underlying mechanisms of what causes MS, and could help us to identify new potential treatments.

Preventing people from developing MS in the first place is the ultimate goal for the MS research community.

Perspective



Chris McNamara has MS and talks to us about his perspective.

Which priorities are important to you?

I could see the value in all of them. However, prevention is very important to me because, as a father, I don't want my children to be at risk of developing MS.

What did you think of the process?

I loved it. It was superbly organised and everyone

involved wanted to make a difference. I loved being around people with different perspectives and viewpoints. It made me think about my own views and challenge them too.

Why was it so important to do this project?

Personally, it gave me enormous satisfaction to get involved. Everyone affected by MS should be able to shape the direction of the search for new treatments; otherwise people affected by MS would be the silent recipients of what others think are important.

3

"Which treatments are effective for fatigue in people with MS?"

Fatigue is a commonly reported symptom – most people with MS will experience fatigue at some point. It can be one of the most disabling symptoms due its huge impact on day-to-day life.

Current strategies for treating fatigue include both using drugs and behavioural interventions, such as exercise programmes, cognitive behavioural therapy and energy conservation strategies.

The evidence for the effectiveness of drug treatments is inconclusive, with very little clear evidence that is helpful for people with MS.

But, the evidence for behavioural interventions is much better. Several studies have reported the benefits of different programmes such as exercise and Cognitive Behavioural Therapy.

HOW WILL WE ANSWER THE QUESTION?

Ed Holloway, Head of Care and Services Research at the MS Society said: "Although we know that fatigue can have a massive impact on people's lives, we still don't fully understand it, or know how to measure it. This means that testing new treatments is really difficult. Often treatments work for some people but not others, or trial results are unclear.

"We will work with our Clinical Trials Network to understand what research needs to take place to improve our understanding of fatigue. We'll then be in a much better place to develop and test new treatments, and to understand if the current treatments really do work."

FACETS study

We funded a study demonstrating the benefits of a group-based cognitive behavioural and energy effectiveness programme for helping people with MS better manage their fatigue.

The course can be run by health care professionals and we are currently supporting training in the intervention. For more information about training opportunities contact education@mssociety.org.uk



Professor Peter Thomas and Dr Sarah Thomas, who led the FACETS study

"Fatigue is really important to me – it is a really significant issue – it is so subjective and people deal with it differently. It's so difficult to both treat and measure. It would be great to have more evidence to help deliver better and better interventions."

Rachel Wallbank, occupational therapist

Want to find out more?

Want a copy of our booklet on Fatigue? Call **020 8438 0999** (weekdays 9am-4pm).

4 “How can people with MS be best supported to **self-manage** their condition?”



A self-management approach is one in which people with long-term health conditions take a more proactive role in managing their health and well-being.

In particular people are encouraged to:

- ▀ find out more about their condition
- ▀ learn new skills and tools to help them manage their health
- ▀ work better, and in partnership, with health care professionals

There are a range of self-management programmes available within the UK, but access to them is mixed.

The quality of evidence for self-management interventions is variable – some programmes have better evidence than others, but we still don’t understand which programme should be offered, and to whom.

OUR PLAN

We will set up a meeting of academics, health professionals, people affected by MS and providers of self-management programmes, to consider the current evidence and the best ways for everyone to access high quality self-management programmes in the UK.

The meeting could recommend we commission reviews of aspects of self-management or carry out large randomised-controlled trials of existing or adapted interventions. As self-management is a broad topic we would expect this to focus on a specific aspect that is relevant to a large proportion of people with MS.

We would also highlight research into self-management as an area of specific interest for researchers to apply for funding through our grant round so that other avenues can still be explored.

Perspective



Neil Kemsley is a carer and Chairman of MS National Therapy Centres. He tells us why improving self-

management for people with MS is so important.

“Everyone involved in MS in a professional capacity needs to engage with the issues people with MS experience on a daily basis.

“My wife’s involvement with her Therapy Centre has been crucial in supporting her approach to self-management, which in today’s world is a really important issue – it ties in with the idea of the expert patient. With limited NHS resources we really need research that will help people take control of their lives and their MS and do these things for themselves. This is hugely important especially in a long-term condition like MS.

“People with MS ultimately hope for a cure, but in the meantime it would be great just to get a good night’s sleep (for example, without waking up in pain).”

Professional perspective



Dr Waqar Rashid is a neurologist who was part of the partnership steering group. He gives his

opinion of the process. “The project was novel – there are so many unmet

needs in MS research and this is really helpful for starting to meet them.

“Agreement of so many people on the top 10 is impressive – I think the process was very democratic in doing this.

“This process is the first step,

not the last. It will be interesting to see how the MS Society and the MS community responds to this list and stimulates other bodies and groups to channel their funding to hopefully take on priorities from this list.”

5 Does **early treatment with aggressive disease modifying drugs (DMDs)** improve the prognosis for people with MS?

Nick Rijke, Interim Director of Policy and Research at the MS Society explained: “There are more and more treatment choices for people with relapsing-remitting MS.

“We need more evidence around when is best to treat and with what type of DMD to help people with MS make these difficult decisions about what is best for them.”

Ideally, DMDs should be made available to people as early as possible. But we don’t know whether it’s better to treat people with MS early with more aggressive therapies (such as

Lemtrada, Gilenya or Tysabri), or whether a more ‘wait and see’ approach is better.

The longest term follow-up study to be published involving an aggressive DMD is a five-year follow-up of a phase 2 Lemtrada trial, which showed a 72% reduction in accumulation of disability and a 69% reduction in relapses in people taking Lemtrada compared with beta-interferon.

HOW CAN WE ANSWER THIS QUESTION?

A clinical trial of all currently available aggressive DMDs

compared with a non-aggressive DMD would help us to answer this question.

We will be establishing a working group through our Clinical Trials Network to design a good quality clinical trial that would answer this question. Then we will be well placed to identify the best way to get it funded.

Want to find out more?

For a copy of our booklet on DMDs? Call **020 8438 0999** (weekdays 9am-4pm).

“We need more evidence around when is best to treat and with what type of DMD to help people with MS make these difficult decisions.”



6 Is **vitamin D** supplementation an effective disease modifying treatment for MS?

Most of our vitamin D is made by our bodies in reaction to sunlight on our skin. MS is more common in areas further away from the equator, where there is less sunshine, suggesting a relationship between vitamin D deficiency and risk of developing MS.



Recent research suggests a lack of vitamin D in early childhood or before birth might increase the risk of developing MS later in life (this is not yet confirmed and is the subject of ongoing research).

Where someone already has MS, it's not clear whether vitamin D supplementation could play a role in managing or altering the

course of their MS.

Dr Susan Kohlhaas, Head of Biomedical Research at the MS Society said: "Many people with MS choose to take vitamin D supplements. We urgently need evidence about both the safety and effectiveness of these supplements for treating MS".

"We urgently need evidence about both the safety and effectiveness of vitamin D supplements for treating MS."

Vitamin D
as a prevention strategy is discussed on pages 11-12

WHAT DO WE KNOW?

In 2013, a 'systematic review' of vitamin D supplementation for managing MS analysed five clinical trials. The review showed the trials were small, with huge variation in the dose and type of vitamin D that was tested and the way they looked for improvements.

A 'meta-analysis' of high dose vitamin D trials in people with MS found no significant association between high-dose vitamin D treatment and risk of relapse compared with a placebo.

WHAT CAN WE DO?

Longer-term, larger studies testing agreed doses of vitamin D are needed. But there are still so many unanswered questions about the best way to design and carry out those studies.

We'll set up a working group through our Clinical Trials Network to look at current evidence, ongoing trials around the world and how to design and conduct clinical trials of vitamin D supplementation in MS. Once some of these questions are answered, we'll be in a better position to fund research that will help us understand the potential role of vitamin D in managing MS.

Research Methods

SYSTEMATIC REVIEWS

examine current published scientific literature in a focused area to try and identify, appraise, select and synthesise all high-quality research evidence relevant to that question.

META-ANALYSIS

combines results from lots of different studies, in the hope of identifying patterns, changes or interesting relationships among the results that you wouldn't see in just one study.

Should I take vitamin D supplements?

Currently, there's not enough evidence to tell whether vitamin D is a safe or effective treatment for MS.

If you're concerned about your vitamin D levels, ask your GP for a blood test. If you are deficient in vitamin D, you may be prescribed a supplement.

The government recommend that people who meet the following criteria take a supplement:

- When it's difficult for someone to get outside
- Women who are pregnant or breastfeeding
- Children aged between six months and five years
- People over 65

It's important to remember that taking too many vitamin D supplements over a long period of time can lead to health problems.

For more info visit NHS Choices www.nhs.uk

7 "Which treatments are effective to improve **mobility** for people with MS?"

Mobility is an extremely broad and complex topic. Mobility includes maintaining and changing body position; carrying, moving and handling objects; walking and moving; and moving about using transportation.

Interventions for mobility are also broad and include drugs, physical, behavioural, medical devices and assistive technology. With so many avenues to explore we don't want to force the research community to focus on one narrow aspect of mobility.

We're already supporting a number of mobility research projects, including a study exploring the cost-effectiveness of Functional Electrical Stimulation (FES) and research we funded last year on falls management (see page 4).



We've also funded work to understand how MS can affect people's gait (how they walk), and to improve balance.

We'll highlight the importance of mobility to applicants to our research grant round, so you can look forward to hearing about more projects in this area in future issues of Research Matters.

Functional Electrical Stimulation (FES)

FES is an assistive device that uses electrical current to stimulate nerves and move parts of the body, which many people with MS find helpful in reducing foot-drop. It stimulates the muscles that lift the foot when walking, making walking easier so someone is less likely to trip or fall.

Want to access FES? Our FES campaigns guide can be downloaded from our website www.mssociety.org.uk



8 “Which treatments are effective to improve **cognition** in people with MS?”

Many people with MS experience problems with cognitive processes such as learning and memory, concentration, mental speed, problem solving and word finding.

Unfortunately, there are few effective treatments for these symptoms, and no reliable way to measure someone’s response to treatments in a clinical trial.

We’re currently funding four projects in this area (read about two of them on page 5). We’re also funding work investigating memory aids for people with MS, and



Cognition research is vital

Gwen Covey-Crump has MS, and was part of the partnership steering group. She told us:

“This is really important to me as it’s the symptom that scares me the most as I feel cognitive difficulties are under-recognised and under-treated.”

understanding how dual-tasking (doing two things at once) affects cognition in people with MS.

A large government research funder recently invited proposals for cognitive rehabilitation for

people with MS, so we hope new funded projects will be announced soon. We’ll now wait for these results while continuing to highlight cognition to researchers applying for grants.

10 “Is **physiotherapy** effective in reducing disability in people with MS?”

‘Physiotherapy’ includes a range of interventions designed to help a wide range of symptoms. For example, a physiotherapist can suggest exercises to help manage problems such as difficulties with mobility, balance, pain, muscle spasms, posture and fatigue.

There’s evidence that physiotherapy is helpful for people with MS, but better and larger studies are needed to convince the NHS to increase its availability.

Crucially, these larger studies might show that physiotherapy is good value for money as well as effective, but without this evidence access will always be patchy.

We’ll work with and support the physiotherapy research community to ensure large, high-quality studies take place. This may include holding meetings to assist the development of large multi-centre trials or making sure that the small pilot studies we fund lay clear groundwork for definitive trials.



Jane Petty, UK Programme Lead (Physiotherapy) at the MS Society told us: “We know people with MS benefit from physiotherapy, but we need more clinical evidence as to when and for how long they should receive it before it can become more widely available.”

9 “Which treatments are effective for **pain** in people with MS?”

Pain can be one of the most difficult ‘invisible’ symptoms of MS to both describe and manage. It can be exhausting and distressing, and can affect mood and the ability to do everyday activities.

Various drug treatments are used to treat pain in people with MS, many with weak evidence for their effectiveness. There are a number of ongoing clinical trials, and some that have recently finished, which we hope will provide some answers.

Once these studies have finished, the area of drug treatments for pain in MS will need to be reviewed. We hope to commission a systematic review within the next two years. We will also highlight pain research to researchers applying for grants.

MS Society pain research

It’s important to establish the quality of life issues MS pain creates. We’re currently funding researchers at King’s College London who will design a self-management intervention for pain and also carry out a systematic review of psychological factors associated with pain in MS.

“It’s important pain has been highlighted. It affects many people with MS and we really need effective ways to help people manage their pain.”

Ed Holloway, Head of Care and Services Research at the MS Society

What’s next?

It’s great we now have our top 10 and our strategies for tackling them, but we will keep working to turn priorities into projects.

This partnership represents a major shift in setting priorities for MS research. It’s hoped the top 10 will help researchers select topics for funding applications and influence the decisions of other research funders.

Encouragingly, this approach has produced clear results for other partnerships such as type 1 diabetes, prostate cancer

and schizophrenia – priorities are now becoming funded research studies. Government funders have already taken up four priorities from three other partnerships. We hope to see similar things happening with ours.

These priorities will complement our existing Research Strategy – we’ll continue to support research into the causes of MS, and treatments and care for people affected by MS.

What happens to the rest of the questions?

Although not all questions made it into our top 10, a record of all 67 questions are on our website for everyone to view.

All questions about the effectiveness of treatments for MS have been entered into the UK Database of Uncertainties of the Effects of Treatments. UK DUETs – www.library.nhs.uk/duets

Getting involved

Here we talk to three people who participated in the final prioritisation workshop. They tell us about their experiences of the project, why they got involved in the first place and their hopes for the future.

Gwen Covey-Crump is a vet from Clevedon who has MS. She was part of the project steering group.

“I found out about the project through an email from the MS Society’s Research Network. I wasn’t aware of

the process prior to getting involved, and was extremely impressed with the way it consulted both health care professionals and people affected by MS about the unanswered questions that they have.

The thing that made me really want to take part is my interest in evidence-based medicine. I also think there’s a real conundrum: with so much research going on, it can be hard to decide what to pursue.

I’m really glad I took part as the whole project was really enjoyable and I was made to feel a real

member of the team throughout. I’m actually sad it ended!

Because of my background as a vet, I think my opinions were a half-way house between a medical perspective and a lay person’s perspective. But I also represent the MS community, my own symptoms are very mild, but I also have friends with many different perspectives of living with MS.

I think the new research priorities will particularly influence the direction of care and services research. Hopefully in the future we will see more evidence of the effectiveness of treatments in this area.”



Gwen Covey-Crump

“There’s a real conundrum: with so much research going on, it can be hard to decide what to pursue.”



Rachel Wallbank is an occupational therapist specialising in clinical neurosciences and is based in Cardiff.

“I wanted to participate in the project because I think it’s important to look at research not just from the perspective of the researchers but also to involve people with MS, carers and professionals. I feel that clinicians and researchers need to be more focused on the real needs of people with MS and those close to them.

As an occupational therapist I think I provided some unique thought and considerations to the discussion. MS affects your entire life, not just you as a patient, but also your friends and family. All these viewpoints should be taken into account when decisions are made about research and treatments.

I think the new priorities will help researchers to focus more on progressive MS. There is now a new drive to look at the issues and this will give hope to people with progressive MS that something is actually being done about it.”



Rachel Wallbank

“I think the new priorities will help researchers to focus more on progressive MS. There is now a new drive to look at the issues.”



Roshni Shah

“I really enjoyed participating in the workshop. It was great hearing other people’s opinions but also to have my voice heard.”

Roshni Shah has relapsing-remitting MS. She is currently living in the Czech Republic while studying for her degree.

“I was diagnosed with MS when I was 19, just before I left for Prague to start my degree in medicine. Since then I’ve become more and more interested in research and wanted to be a part of it in any way possible.

I really enjoyed participating in the workshop. It was great hearing other people’s opinions but also to have my voice heard. There is sometimes a sense of uselessness when you have MS but this whole process made me feel like I was not

just heard but that I was contributing on behalf of all young people with MS.

By setting research priorities in this way, it gives power back to patients and health care professionals, allowing them to have their say on what’s important to them. Ultimately

research must focus on what would benefit people with MS the most.

The top 10 questions will give researchers an insight into what people affected by MS want to know. Now they can get to work on answering them.”

To find out more
about the project visit
www.mssociety.org.uk/jla

Be part of it

There are many ways you can get involved in the work of the MS Society and feel part of the MS community. Why don't you join us at MS Life this year in Manchester or host your own Cake Break.



Visit MS Life 2014

Join over 3,000 people from across the UK at MS Life – the biggest FREE lifestyle and information event on the MS Society calendar.

During MS Life 2012, we ran 45 workshops and seven research talks over the weekend, delivering over 52 hours worth of information!

This year you'll be able to hear from some of the UK's top MS researchers on a wide range of topics. Speakers include Professor Robin Franklin on the latest developments in myelin repair research.

In an MS Life first, we'll have a 'science zone' where you'll be able to question the scientists and take part in interactive activities.

See you there

Saturday 26 April and Sunday 27 April 2014 (10am-5pm)
Manchester Central Convention Centre, Manchester, M2 3GX

Want more information?

If you have any questions about MS Life, or about financial support available you can visit: www.msLife2014.com or contact the MS Life team: Email: mslife@mssociety.org.uk Telephone: 020 8438 0941 (weekdays 9am-5pm)



Cake Break 2014

Cake Break is a scrumptious, creative and social way to raise money for vital MS research projects.

It's simple. Invite your friends, family or anyone you know who likes eating cake, and dazzle them with an abundance of tasty treats, and then watch the donation box fill up. We'll provide you with a free Cake Break host pack, containing all the information you'll need to organise an amazing event, along with helpful tips on how to make your Cake Break a huge success, and also bunting and balloons for you to use for your Cake Break.

Hundreds of cake breakers across the UK have already registered for Cake Break 2014. If you'd like to join them, please go to our dedicated website www.cakebreak.org.uk for all things Cake Break or contact the Cake Break team at cakebreak@mssociety.org.uk or 0845 481 1577 (weekdays 9am-5pm).

Let's get baking to beat MS!



Get involved in research

Visit www.mssociety.org.uk/research to find out about all the ways you can get involved in MS research.

You could:

- join the UK MS Register
- register with the MS Society Tissue Bank
- be in a clinical trial or research study
- help shape research by joining our Research Network

You can help beat MS

Your support is vital if we are to continue funding research projects like these.

Call 0800 100 133 or visit www.mssociety.org.uk/donate to see how you can make a donation.



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Do you have ideas about how we could improve Research Matters?

Please send them to
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