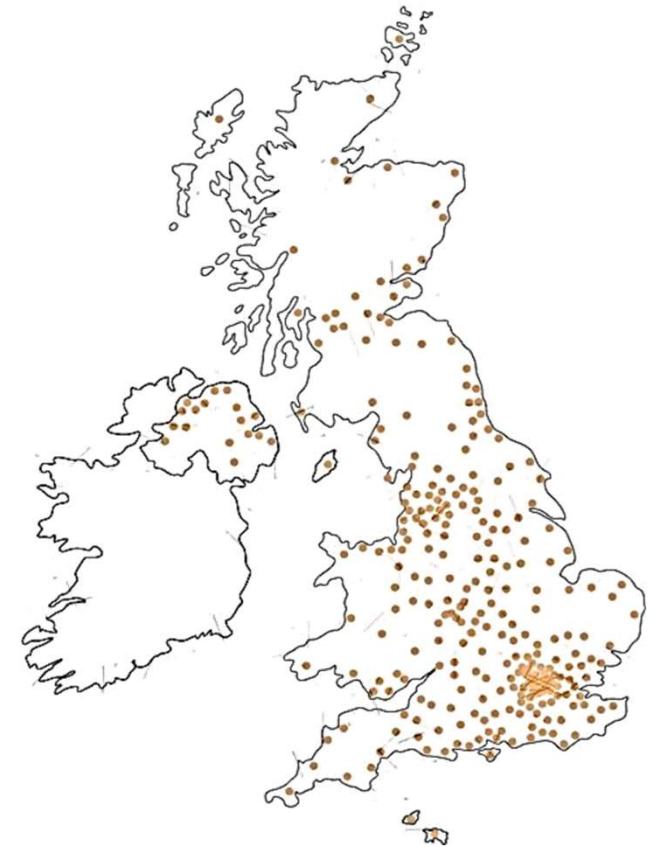


HSCT & the MS Society

Madeleine Walpert and Ruth MacLeod, policy team, MS Society

The MS Society- who are we?

- ▶ A community of people living with MS, friends, families, carers, scientists, healthcare professional, campaigners, volunteers and staff.
- ▶ On the phone. Online. In person.
- ▶ Across the UK, nationally, regionally and locally (including through over 250 local groups)



UK MS Charities

- ▶ MS Trust
- ▶ AIMS
- ▶ Shift.MS
- ▶ and more!



Our work on HSCT

▶ **Providing information and raising awareness**

- We develop evidence-based information resources
- We amplify voices of people who've had HSCT
- We provide quotes/comments for media

▶ **Working to improve access**

- We advocated for HSCT to be approved on the NHS in England and Scotland
- We chaired roundtables with other charities and clinicians

▶ **Supporting and funding research**

- We helped bring people together to develop the StarMS trial
- Funding of Star-MS add-on trial
- We fund HSCT projects through open grant rounds

Our community and HSCT

- ▶ We hear lots of stories from people with MS who've had HSCT
- ▶ People who've had it on the NHS, privately in the UK, or abroad. People with different types, and in different stages of MS
- ▶ We know that for some people it can be truly life-changing
- ▶ We also know it doesn't work for everyone
- ▶ We help people tell their stories...

Our community and HSCT

- ▶ We know HSCT can be life-changing
- ▶ We also know it doesn't work for everyone
- ▶ We help people tell their stories...



Miles' HSCT journey.

In 2017, Miles travelled to Mexico for HSCT, two years after being diagnosed with relapsing MS. He told us he'd made the decision because his mobility had rapidly declined. Find out how he's doing now, four years after treatment.



"Everything is different now" - Roy's HSCT story.

Roy is 49 and has lived with MS for 15 years. Last year he had HSCT at Imperial College London. This is what happened.



What I wish I'd known about HSCT

I chose to opt for HSCT in Mexico despite being turned down for a trial in the UK. Instead I was hopeful and ready to get well and believe in the process.



My journey to HSCT on the NHS

Shereena was diagnosed with MS in 2009 at the age of 17. Now she is beginning HSCT treatment on the NHS.



"I've got nothing to lose" - Steve and Lucy Kerly's HSCT journey.

Lucy Kerly and her husband Steve both had HSCT to treat their MS. Lucy has just had HSCT on the NHS at Hammersmith Hospital in London. Steve travelled to Mexico for his in 2016. Lucy tells us about their experiences and how they're both getting on.

Our community and HSCT

- ▶ ...and learn from each others' experiences



HSCT insights: "It wasn't the right option for me"

My first symptom was a numb hand. As I was in my final year of exams at university, I ignored it and put it down to stress.



HSCT insights: dealing with isolation

What's it like having HSCT? Three people who've had the treatment share their experiences.



A carer's guide to HSCT

Caring for someone having HSCT is no small task. Sure, you're not the one undergoing the medical treatment. But it's still quite a big responsibility that shouldn't be taken lightly.

Providing media comments

THE YORKSHIRE POST

News you can trust since 1754

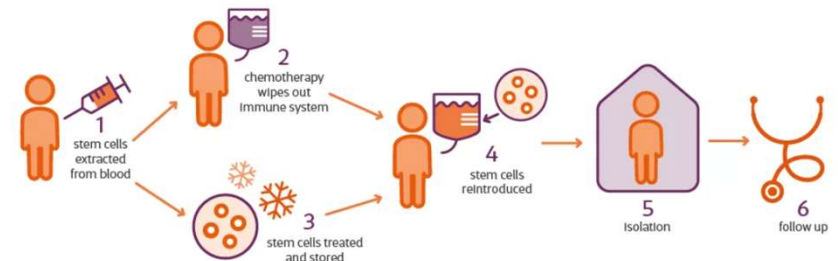
Sport Property TV Business Opinion Lifestyle Heritage Country and Farming

“The documentary follows her as she decides to have stem cell treatment, or HSCT, for her MS. We know this intensive treatment is likely to be most effective when people with MS, like Selma, are having lots MS attacks or there’s evidence of inflammation on an MRI scan. In the UK, HSCT is available on the NHS but eligibility criteria are strict and it can be difficult to access. We’re calling for everyone who is eligible to be able to get the treatment on the NHS, if they want it.”

- Dr Sarah Rawlings, MS Society’s Executive Director of Research & External Affairs

Information provision

- ▶ MS Helpline, webpages, booklets, newly diagnosed events etc.
- ▶ We want everyone with MS to have a full picture of all their treatment options
- ▶ We involve people with MS who've had HSCT in creating new and updated information



HSCT for MS

31 March 2023

HSCT (haematopoietic stem cell transplantation) is an intense chemotherapy [treatment for MS](#). It aims to 'reset' the immune system by wiping it out and then regrowing it, using your stem cells.

> [Read our tips for talking about HSCT with your doctor or nurse](#)

In this section

About MS

Information provision

- ▶ MS Helpline, webpages, booklets, newly diagnosed events etc.
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- ▶ We involve people with MS in creating new and updated information



HSCT: what to expect

26 May 2022



HSCT is a hugely promising treatment for MS, but it is also very intense. This means that it comes with risks and there are lots of factors to consider.

If you're considering having HSCT, we recommend you talk to your neurologist about whether it's the right treatment for you.

> [Read our tips for talking about HSCT with your doctor or nurse](#)

Jump to:

- [Do I qualify to get HSCT on the NHS?](#)
- [What happens during HSCT?](#)
- [What should happen after HSCT treatment?](#)
- [How do I get HSCT?](#)
- [COVID-19 and HSCT](#)

In this section

About MS

Treatments and therapies

Disease modifying therapies

Early treatment

COVID-19 coronavirus and MS treatments

HSCT information

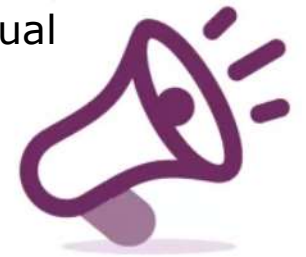
- ▶ We reflect EBMT guidelines and take advice from clinicians
- ▶ We talk about HSCT in the same terms we talk about other DMTs
- ▶ Our information aims to help people understand:
 - How HSCT works
 - How well it works and possible side effects
 - How you get HSCT and who qualifies for it on the NHS
 - What happens during and after HSCT
 - How to talk about HSCT with your health care professional

Explore disease modifying treatments for MS

- + Alemtuzumab (Lemtrada)
- + Avonex (interferon beta-1a)
- + Betaferon (interferon beta-1b)
- + Cladribine (Mavenclad)
- + Daclizumab (Zinbryta) - withdrawn
- + Dimethyl fumarate (Tecfidera)
- + Diroxime fumarate (Vumerity)
- + Extavia (beta interferon-1b)
- + Fingolimod (Gilenya)
- + Glatiramer acetate (Copaxone)
- + HSCT
- + Natalizumab (Tysabri)
- + Ocrelizumab (Ocrevus)
- + Ofatumumab (Kesimpta)
- + Ozanimod (Zeposia)
- + Plegridy (peginterferon beta 1a)
- + Ponesimod (Ponvory)

Access to treatments

- ▶ People with MS should have fair and equal access to treatments wherever they live.
- ▶ But this isn't happening.
- ▶ We want to make these goals a reality:
 - All recommended treatments are available on the NHS to everyone eligible for them
 - Regular reviews of treatment and care by MS specialists for everyone with MS
 - Accessible information about treatment options, and support to be equal partners in decision-making, available to everyone with MS



[#SpeakupforMS](#)

Access to HSCT

- ▶ We want everyone who is eligible, to be able to access HSCT on the NHS
- ▶ Our position is informed by clinicians
- ▶ We've been involved in positive changes
 - Part of NHS England working group that developed treatment guidance which made HSCT available for the NHS in England for the first time
 - Helped advocate for the approval of HSCT in Scotland by the Scottish Health Technology Group

Access to HSCT

- ▶ We're not there yet!
- ▶ We still hear from people who haven't been able to access HSCT on the NHS, despite being eligible.
- ▶ Hospitals need enough resource and support to provide high quality treatment and aftercare
- ▶ Patients need access to professionals who are well-informed about HSCT
- ▶ Patients need clear guidelines and criteria



Tips for talking about HSCT

7 June 2023



If you're wondering if HSCT is an MS treatment that's right for you, these tips can help you and your MS team have a clear and useful discussion. You might find the tips helpful for discussing other MS disease modifying therapies too.

We've worked with people with MS and care professionals who've had conversations about HSCT. The people with MS told us that when they raise HSCT with a care professional, they want:

1. To understand if HSCT is right for them – and if it's not, why not
2. To know about their treatment options

In this section

[About MS](#)

[Treatments and therapies](#)

[Disease modifying therapies](#)

mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies

Do I qualify to get HSCT on the NHS?

The NHS have criteria for who can get HSCT. These criteria refer to guidance from the European Society for Blood and Marrow Transplantation (EBMT).

But they don't match up completely and there might be differences in how the guidelines are applied at the centres offering HSCT in Sheffield and London.

[Clinical trials for HSCT](#) might have slightly different criteria.

Going abroad

- ▶ Some people with MS, frustrated at not being able to access HSCT on the NHS in the UK, may pay privately to access it in the UK
- ▶ Others may decide to go abroad. This could include people who want to try HSCT as a first treatment, or who don't show signs of active inflammation
- ▶ The main clinics we're aware of people travelling to are in Mexico and, previously, Russia.
- ▶ We believe it's important clinics keep and share follow-up data on patients, so their results can be scrutinised.
- ▶ It's vital people who do go abroad for HSCT, receive the proper after-care

Having HSCT abroad

If you're considering having HSCT abroad, there are several things to consider:

1. Find out exactly what the clinic is offering, and how experienced they are

HSCT is not the only type of stem cell therapy being researched in MS. Mesenchymal stem cell therapy is also being investigated but this is still at the clinical trial stage. Make sure the clinic you are considering is offering HSCT specifically.

It's also worth checking how experienced the clinic is at providing HSCT for people with MS. Are there examples of other people with MS benefiting from HSCT at this clinic? Do they also offer the treatment for many other conditions? This may suggest the clinic is not specialised for MS. Some centres have published research about HSCT treatment.

2. Is the clinic regulated to international standards?

Going abroad

Things to consider

1. Find out exactly what the clinic is offering
2. Is the clinic regulated to international standards?
3. What follow up care is provided?
4. What's included in the cost?

2022 HSCT roundtables

- ▶ Clinicians and charities
- ▶ Focus on how to improve access
- ▶ Aiming to build a consensus
- ▶ Discussion topics included
 - Clinical evidence base for HSCT
 - Educational pieces for clinical community
 - NHS infrastructure supporting access to HSCT
 - StarMS recruitment

2022 roundtables

▶ Conclusions included....

- Clinicians attending agreed HSCT should be available as a clinical option for first-line treatment in some cases of relapsing remitting MS. As NHS capacity rarely allows for this – it would be best in a trial setting
- MS Society to develop information resources to support patients in having conversations about HSCT with clinicians
- Agreed that StarMS is vital to improving HSCT access on the NHS in the long term

Research

- ▶ StarMS is vital to improving access
 - Evidence could help clinicians feel more confident in referring patients for HSCT and other high efficacy DMTs
 - If positive, evidence from trial could make it easier to access HSCT on the NHS
 - StarMS trial sites around the UK - training new centres to do HSCT will expand capacity
 - Add-on studies will tell us more about how it works



Understanding how chemotherapy used in HSCT affects nerves



Lead researcher: Dr Sharmilee Gnanapavan

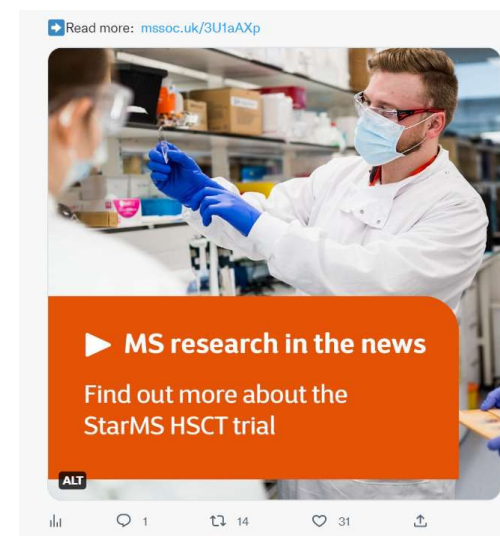
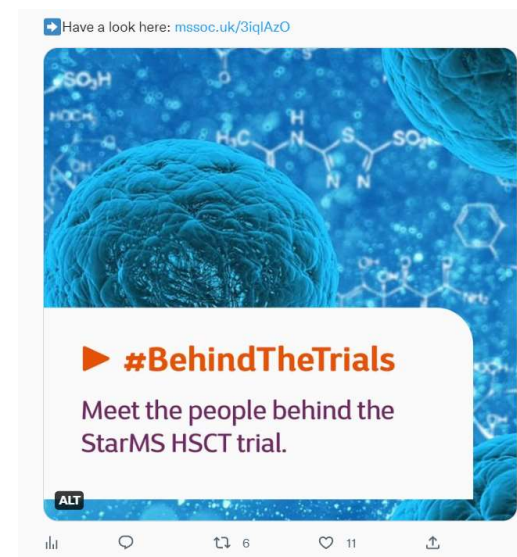
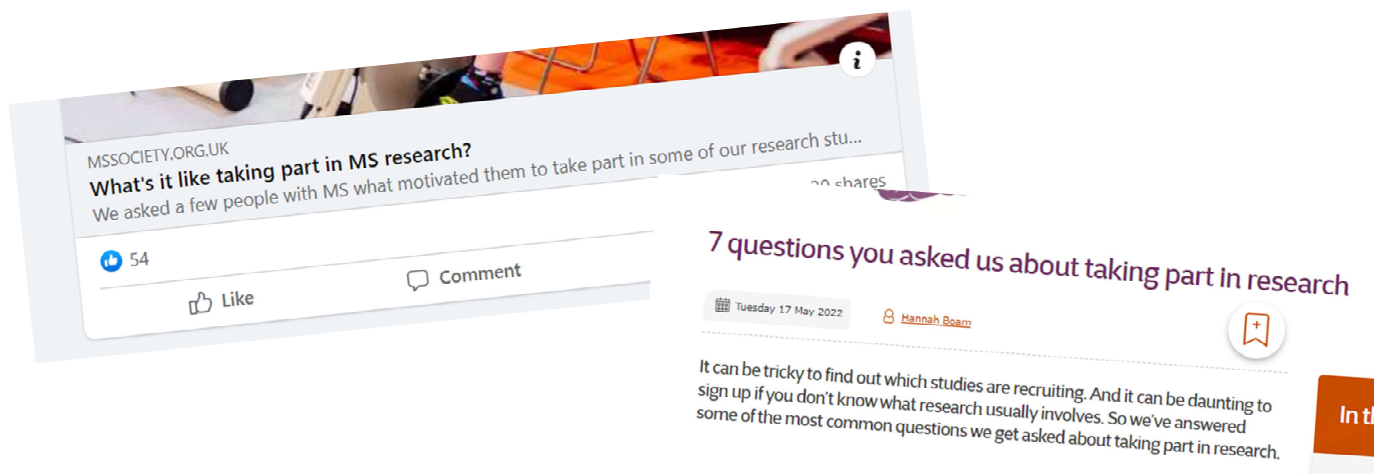
Based at: University College London

MS Society funding: £39,473

Status: Active

Research

- ▶ Helping make StarMS a success is a priority
 - Patients need to be informed and empowered to raise clinical trials with clinicians
 - Patients need to feel at ease with idea of clinical trials
 - Clinical community need to be aware and informed of options for their patients



Thank you!

