MS Society

Research matters

The latest developments, innovations and achievements in MS research

Summer 2018 · Issue 015

Stem cells and MS

Revealing their potential

PLUS

Your questions, HSCT, and clinical trials

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WELCOME TO RESEARCH MATTERS

STEM CELLS HOLD a lot of promise for medical research, both as laboratory tools and as treatments. They also continue to make the headlines, as stem cell therapy comes to the forefront of medical science.

While definitely an exciting time for MS research, it's also a time for getting the facts. We think people deserve to be properly informed about what stem cells can – and can't – offer. We hope this issue of Research Matters gives you the information you need to make the right decision for you.

There are lots of different types of stem cells, and in this special stem cell issue we introduce the ones most important for MS research.

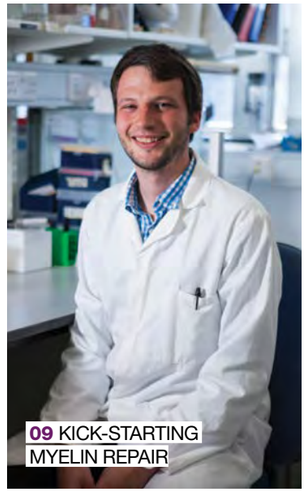
Haematopoietic stem cell transplantation (HSCT) for MS is available on the NHS. But so far using intensive chemotherapy to tackle MS has only been shown to be suitable for a select number of people. You can read about the latest clinical trial results for HSCT on **page 17**.

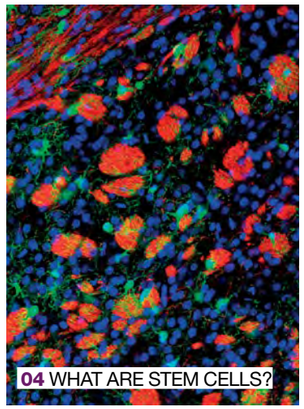
Experimental mesenchymal stem cell therapy made the news last autumn, with a powerful documentary charting the hopes of Mark Lewis, and the challenges he faced, as he underwent the procedure for MS. We look at what clinical trials for mesenchymal stem cell therapy have shown so far on **page 14**.

We're also really excited by what researchers are learning from stem cells in the lab. Using them, it's now possible to grow any type of tissue and study what goes wrong in MS under the microscope. You can read about this exciting work taking place at our Edinburgh Centre on **page 11**.

As always, we'd love to hear what you think. Our team answer your questions on stem cells on **page 12**, but you can also share your feedback with us using the contact details on the left.

Susan Kohlhaas
Director of Research





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talk

If you'd like to talk to someone in confidence about any of the topics raised in the magazine, the MS Society Helpline is there to listen. You can call them for free on **0808 800 8000**, or email **Helpline@mssociety.org.uk**

Research Matters is available as an audio download. For details, telephone **020 8438 0999** or visit **mssociety.org.uk/Research-Matters**

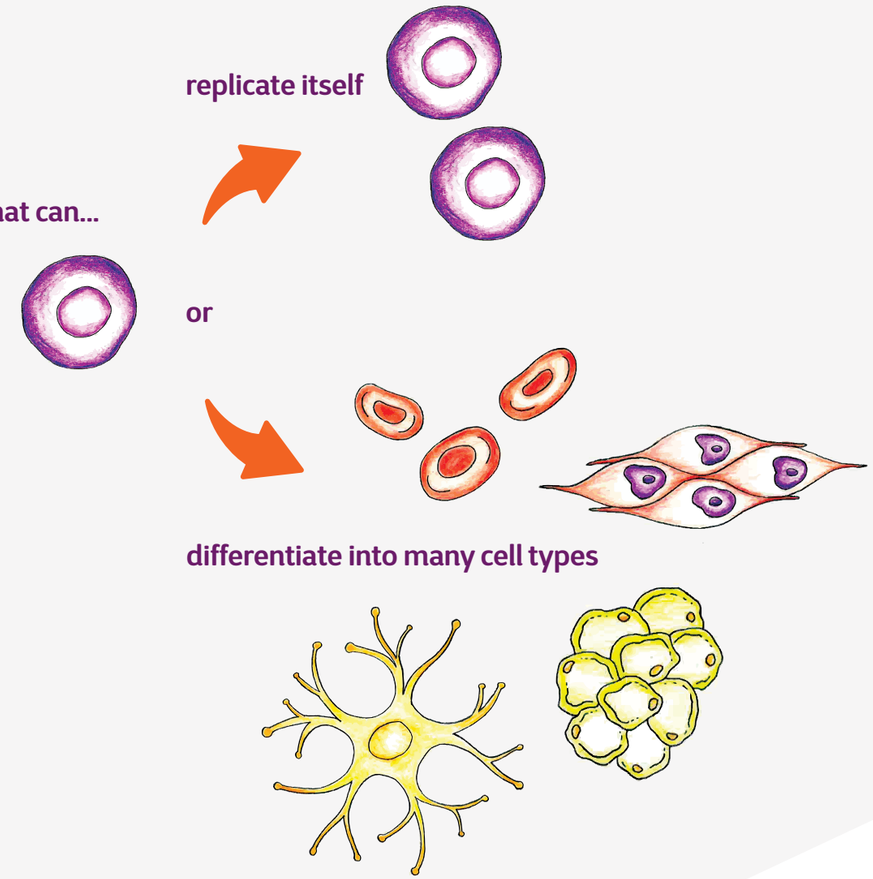
WHAT ARE STEM CELLS?

Stem cell research has come on leaps and bounds over the past few decades, and shows great promise for finding treatments for MS

What are stem cells?

Most of the cells in our bodies carry out very specific roles. For example, red blood cells carry oxygen around the body, while nerve cells send messages to each other in the brain and spinal cord. These are called specialised cells.

Stem cells are different because they aren't specialised. This means they have the potential to become lots of different types of cell. They're really important during development, and can also repair damage and replace cells as we age.



Embryonic and adult stem cells

When people think of stem cells, they tend to think of cells found in developing embryos. These embryonic stem cells have the potential to grow into any of the cells found in the body, and can be used in research to help us learn more about how our bodies develop.

But there are also stem cells found in the adult body. These adult stem cells are found in lots of different tissues, from our bones to our brains. Unlike embryonic stem cells, adult stem cells can't make all the different cell types in our bodies – what cells they can produce depends on the type of adult stem cell they are.

There are three types of adult stem cells that scientists are interested in for MS treatments.

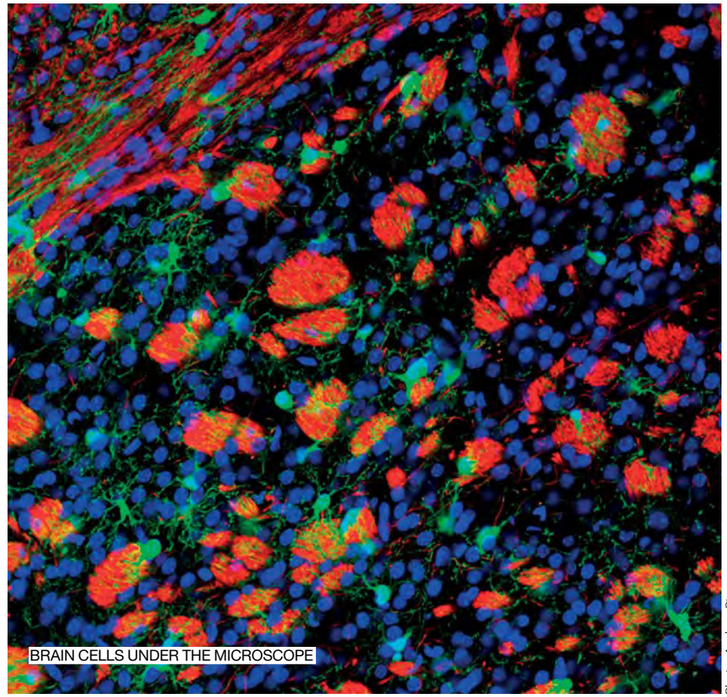

BRAIN CELLS UNDER THE MICROSCOPE

Photo: Andrea Rivera

1. Haematopoietic stem cells

All of the cells in the blood, including immune cells, are made by haematopoietic stem cells. These stem cells are an exciting area of research for MS, with haematopoietic stem cell transplantation (HSCT) already used as a treatment for MS.

2. Mesenchymal stem cells

Mesenchymal stem cells are found in many parts of the body and are usually taken from bone marrow, skin and fat tissue. They can make many different types of cells, including muscle and cartilage.

But it's the molecules produced by mesenchymal stem cells that are of the most interest to MS researchers. It's thought that these molecules can have a positive effect on the immune system, and may also help to promote myelin repair.

3. Neural stem cells

Neural stem cells are found in our brains. They produce the cells of our central nervous system, including myelin-making cells, called oligodendrocytes. Researchers are working to harness the power of these neural stem cells to promote myelin repair in MS.

Stem cells as a research tool

As well as investigating adult stem cells found in the body, researchers are now able to make embryonic-like stem cells in the laboratory, known as induced pluripotent stem cells (or iPS cells). This amazing technology is helping our scientists study MS in live human tissue.

MEET THE EXPERT

Neurologist Professor Neil Scolding, from the University of Bristol, explains the potential of stem cells in MS research

'A **MIRACLE CURE FOR** MS' seems to be a favourite headline in our national press. Every few years we see it, in one form or another. Of late, the words 'stem cells' are almost always included. Most of us interested in MS have learned to be a little sceptical of such headlines. We know, after all, that 'scientists cautiously report small research advance' makes a poor headline. But behind the headlines, what's going on? What progress has there been, and how close are we to seeing stem cell therapies routinely used in an MS clinic?

The answer is – it's complicated, and has become even more so over the past few years. In fact, we now think of stem cell therapy in MS in three very different ways:

1. Targeting the immune system

In the first, most well-known, type of stem cell therapy, the aim is to replace the misfiring immune system with a normally functioning one. This is done with chemotherapy and haematopoietic stem cell transplantation (HSCT). Clinicians in London and Sheffield, often working closely with international colleagues, are currently exploring this approach with considerable success.

While still not a 'routine' treatment, we have an increasing understanding of the potential benefits – and the clinical risks – of this approach.

PROFESSOR NEIL SCOLDING

2. Limiting the damage

Research suggests that mesenchymal stem cells (MSCs), often taken from the bone marrow, can help protect the nerves from immune attacks, and may also be able to promote myelin repair.

The therapy is still early on in its development. But larger clinical trials are underway, including the international MESEMS study, which is due to report next year.

In Bristol, we're conducting a phase 2 trial of MSC therapy. The 'Actimus' trial is treating 80 people with longstanding MS – some with primary progressive and some with secondary progressive MS.

Time will tell if this helps! The trial is fully recruited, but we won't have the final results before the end of next year. At present, MSC therapy remains an experimental approach, but over the next few years we hope to begin to provide answers as to whether this will genuinely make a difference to people with MS.

3. Promoting myelin repair

UK scientists have long been at the international forefront of finding ways to replace damaged myelin and oligodendrocytes in the brain and spinal cord.

Researchers in Cambridge are looking at whether injecting neural stems into the central nervous system could be an effective way to increase myelin repair. This idea, though one of earliest stem cell therapies to be thought of for MS, remains the most experimental and the furthest from the clinic.

Researchers are also looking at ways to kick-start the neural stem cells that already exist in the brain. It's hoped that by understanding more about how neural stem cells promote myelin repair, we can find drugs that can boost this process. One such drug (bexarotene) is now in clinical trial.

STEM CELLS

	Haematopoietic stem cells (HSCs)	Mesenchymal stem cells (MSCs)	Neural stem cells	Induced pluripotent stem cells (iPS cells)
Where they are	Bone marrow	Bone marrow, skin and fat tissue	Brain	In the laboratory
What they do	Can become the different cells of the blood, including immune cells	Can become a variety of cell types, including bone cells, cartilage cells, muscle cells, and fat cells	Can become the different cells of the central nervous system, including nerves and myelin-making cells	Can be produced from adult cells in the laboratory and then turned into any cell of the body
How we use them	HSCT is used to 're-set' the faulty immune system, which can be very effective in treating highly active MS	Scientists think the molecules produced by MSCs can help dampen down the immune response and encourage myelin repair	Researchers are looking at ways to encourage these cells (and the cells they make) to produce more myelin-making cells	To create human nerve cells and myelin-making cells that model MS in the laboratory
Read more	Page 16	Page 14	Page 8	Page 11

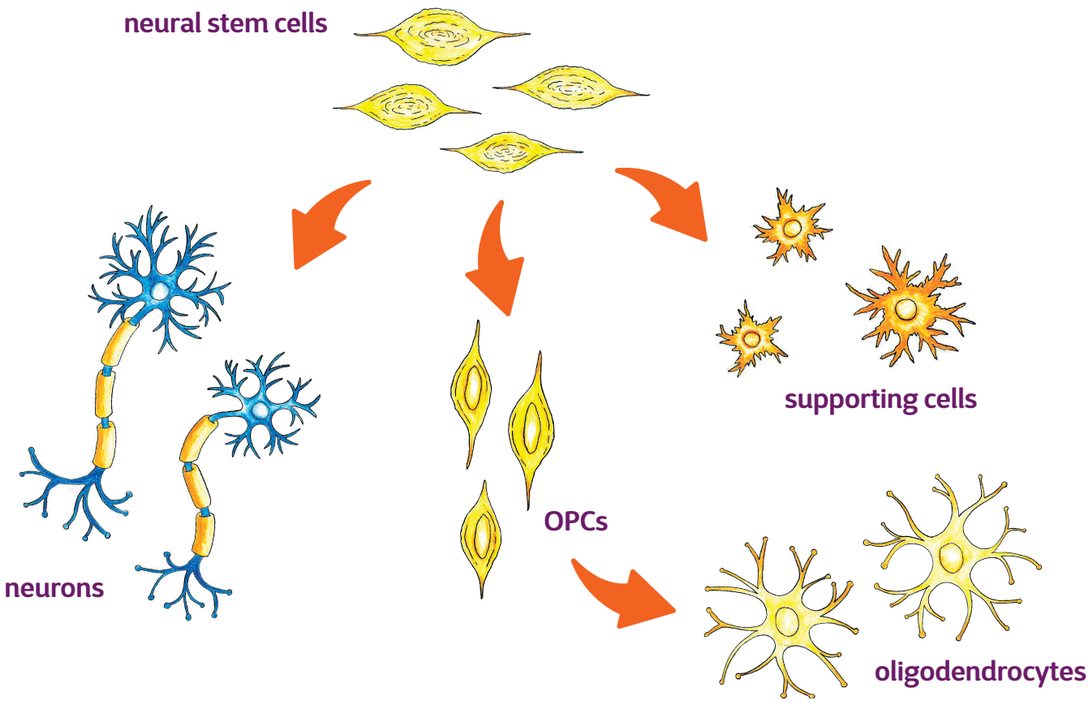
HARNESSING OUR NATURAL ABILITY TO REPAIR MYELIN

Just 20 years ago, a discovery was made that forever changed our understanding of how the brain works, and this discovery has also changed the way we look at MS.

FOR DECADES IT was believed the brain was a fixed system that couldn't regenerate or repair itself. But in 1998, a group of Swedish scientists showed that new nerve cells could form in the adult brain. Further research found that these new nerves developed from a type of stem cell called a neural stem cell.

In fact, these amazing stem cells can generate all the main cells of the nervous system: nerve cells, myelin-making oligodendrocytes, and the other supporting cells in the brain (known as glial cells).

Neural stem cells have opened up a whole new avenue of research into neurodegenerative conditions. For MS, the focus has been on how to encourage neural stem cells to develop into cells that can repair myelin.



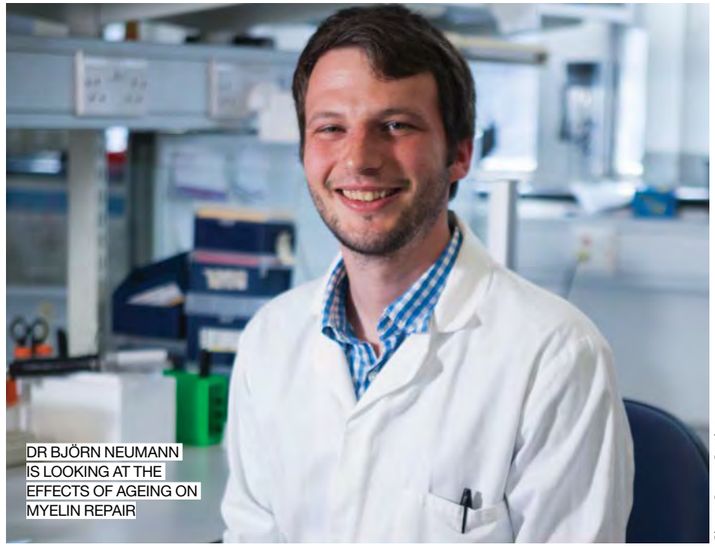

DR BJÖRN NEUMANN IS LOOKING AT THE EFFECTS OF AGEING ON MYELIN REPAIR

Photo: Simon Rawles

Kick-starting myelin repair

Our dedicated team in Cambridge are finding ways to promote myelin repair

AT THE MS SOCIETY Cambridge Centre for Myelin Repair, the team are looking at why OPCs stop responding to myelin damage over time – and finding out what can be done to kick-start these stem cells back into action.

Dr Björn Neumann is focusing on the effects of ageing on OPCs. We know that myelin repair gets worse as we get older but we don't know why. Björn's been using young and old rodents to see what changes in their stem cells make them stop responding.

Lifestyle changes

As well as looking at what goes wrong, Björn is also investigating whether certain lifestyle changes can help rejuvenate OPCs back to their younger state.

Interestingly, diet has come up as a promising avenue to investigate. Extreme calorie restriction in rats seemed to increase their levels of myelin repair, even in the older rats. This increase in the levels of myelin repair comes from an increase in the number of OPCs responding to myelin damage and developing into oligodendrocytes.

Studies are at an early stage, but it's definitely an exciting time in the world of myelin repair research. The team are currently looking at what happens in the cells after fasting, and seeing if they can achieve the same effects with medicines.

watch You can find out more about Björn's research in our Meet the Researchers video series: **https://www.youtube.com/watch?v=Ag0vdJOAqsI**

A cry for help

Oligodendrocytes in the brain and spinal cord can efficiently repair damage to myelin as well as strengthen existing nerve cell connections.

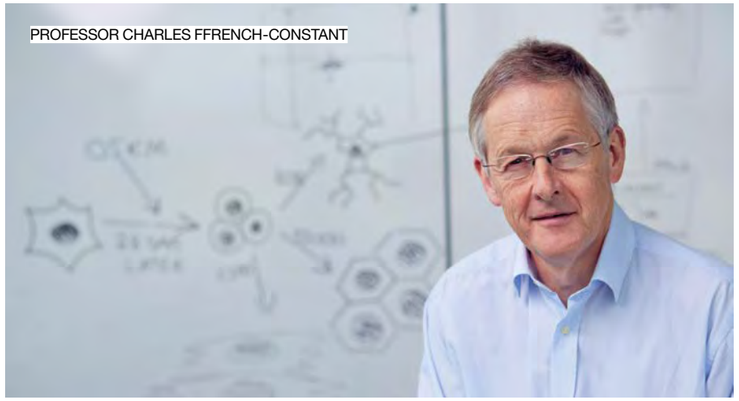
Oligodendrocytes are made from oligodendrocyte precursor cells (OPCs), which themselves develop from the neural stem cells.

It's thought that when nerve cells are damaged, they signal to the OPCs, which then travel to the site of damage and mature into oligodendrocytes, ready to replace the lost myelin.

In both MS, and as we age, this repair process slows down. OPCs stop responding to the nerve's cry for help and myelin damage builds up. Experts think it's this slowing down of the brain's ability to repair myelin damage that could lead to progressive MS.

Harnessing the potential for nerve repair

Recent research suggests that OPCs can do more than repair myelin. They can also help repair damaged nerves



THE PROGRESSIVE STAGE of MS is dominated by damage and loss of nerve fibres in the brain and spinal cord.

Without these nerve fibres, messages can't get sent along the nerves, causing the symptoms of MS. As more nerve fibres are lost, symptoms get worse.

In order to stop – or even reverse – MS progression, we need to find ways to protect and repair damaged nerve fibres.

A new understanding

We used to think that if part of a nerve was damaged, it couldn't be repaired. But studies of spinal cord repair have shown that nerve fibres can grow back, as long as the nerve cell body is intact, and the conditions are right.

Professor Charles ffrench-Constant and his team at the MS Society Edinburgh Centre for MS Research are looking at what factors influence nerve fibre regeneration and what happens in MS.

Early research has shown that oligodendrocyte precursor cells (OPCs), as well as promoting myelin repair, can also encourage the regeneration of a damaged nerve fibre. And this can help prevent the entire nerve cell from dying.

One surprising result of this research is that adult oligodendrocytes seem to block nerve fibre regeneration, rather than promote it.

Investigating further

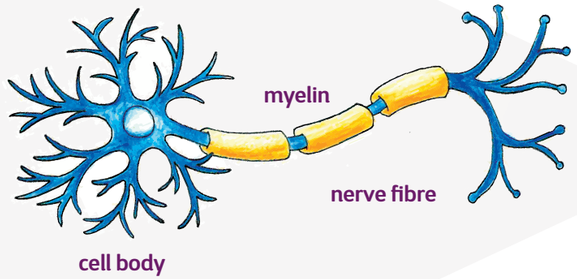
The next step is to try to understand more about the relationship between OPCs, oligodendrocytes and nerve fibre repair in MS. The team are using post-mortem brain samples from people with MS to take a look at this.

Next, they'll see if they can promote nerve fibre repair by changing the levels of oligodendrocytes and OPCs, looking in a mouse model of MS.

A balancing act

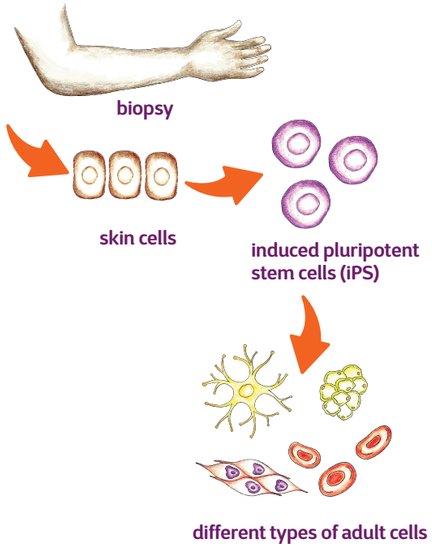
The research is still at an early stage. But it looks like there needs to be careful balance between the number of OPCs and oligodendrocytes in an MS lesion to encourage repair. Too few oligodendrocytes and lost myelin isn't replaced, but too many oligodendrocytes and the nerve fibre can't regenerate.

It's an important problem to solve, because if we can find a way to encourage nerve fibre regeneration in MS, we'd be closer to preventing MS-related disability from becoming permanent.



MODELLING MS IN A DISH

A powerful new tool to help us understand what happens in MS



PROFESSOR SIDDHARTHAN CHANDRAN, Co-director of the MS Society Edinburgh Centre for MS Research:
'iPS cell technology is game-changing for neuroscience research. Before this, we were unable to access living human brain material to study. For every other major disease such as cancer or lung disease etc. you can take a biopsy and study living cells. So for us now, simply being able to study living brain cells, from nerves to oligodendrocytes, in a dish is spectacular progress.'

IMAGINE BEING ABLE TO take a human skin cell and change it into a nerve cell, or a myelin-making cell, or an immune cell, just by adding a few chemicals. It sounds like something out of a science fiction novel, but thanks to Nobel Prize winners Sir John Gurdon and Shinya Yamanaka, it's now a reality.

Researchers can now take skin samples from a person and, in the lab, push these adult skin cells back into being stem cells. These 'induced' stem cells have the potential to become any cell in the body. Because of this, they are known as 'induced pluripotent stem cells', or iPS cells.

A multi-purpose tool

iPS cell technology has opened up a whole new avenue of research, which our scientists at the MS Society Edinburgh Centre for MS Research are taking full advantage of. Led by Professors Charles ffrench-Constant and Siddharthan Chandran, they are using iPS cells to grow unlimited numbers of human-derived nerve cells and myelin-making oligodendrocytes in a dish.

By using skin samples taken from people with MS, the researchers can grow nerve cells and oligodendrocytes that 'model' the condition. Add in some immune cells and you have an insightful tool to study aspects of MS in a laboratory dish. Right now, the team in Edinburgh are using these cells to screen potential drugs and to learn more about what happens during progressive MS.

YOUR QUESTIONS ANSWERED

We answer your questions on stem cell treatments and research

Why has it taken so long for HSCT to come to the forefront of MS research?

HSCT has been around for a long time, particularly as a treatment for blood cancer. But the more we learnt about the role of the immune system in MS, the more it became clear that HSCT might be a good treatment option for this as well. This was back in the 1990s.

Since then, clinical trials have been underway. But the trials haven't been that comparable – using different treatment regimes, looking at people at different stages of their MS, and using various outcome measures. So it's been difficult to draw firm conclusions on the effectiveness of HSCT.

As more results come through, confidence continues to grow in the effectiveness of HSCT, and it's now available on the NHS for those who we know it can help. But there's still work to be done. For example, we need to find out where HSCT fits in as a treatment option for MS. Many of the leading experts on HSCT for MS are calling for a clinical trial to compare the therapy with the leading DMTs such as alemtuzumab (Lemtrada), to give us an answer about which is more effective.

At the moment HSCT is a high risk treatment that isn't suitable for everyone. Is there any prospect of a less intense version that could be more widely used?

HSCT works on the immune system, so it works best for people who are still experiencing active inflammation, usually seen in relapsing MS. And as it's such an intensive treatment involving chemotherapy, it's currently only recommended for people who have highly active relapsing MS despite taking a DMT.

A less intensive version would mean lowering the levels of chemotherapy, which would make the treatment less likely to work.

For people with relapsing MS who aren't suitable for HSCT, there are around a dozen DMTs available, all of which also target the immune system. Though they do come with their own side effects, drug DMTs are less intrusive than HSCT and can be very effective at controlling MS. It's about finding a treatment that works for you and your MS.


Photo: Simon Rawles

ask If you'd like to talk in confidence about any aspect of living with MS you can call our Helpline free on **0808 800 8000**, or email **Helpline@mssociety.org.uk**

As MS is a progressive condition, will people getting HSCT need to have it more than once?

The honest answer is we don't know yet. The question is whether after being reset, the immune system goes wrong and starts attacking myelin again. We funded research at Imperial College that found that the composition of immune cells changes after HSCT, which may suggest that the immune system won't go wrong again. But the longest follow-up we have after someone had HSCT is 13 years. And that's just in one person. We need much longer follow-up of many people after HSCT to be able to properly answer the question.

Can stem cells help with progressive MS?

Stem cells hold huge potential and definitely have a role to play in helping us stop progression, although this may be by aiding discoveries in the lab rather than as treatments. You can read more about using stem cells as tools to understand MS on **page 11**.

HSCT is only expected to help people with active inflammation, usually seen in relapsing MS. Trials in people with advanced progressive MS have shown very little benefit from the treatment.

For mesenchymal stem cell therapy, results so far have mainly shown its potential in tackling the immune system. But early results in mice suggest it could also protect nerves and aid myelin repair, both of which are important for tackling progressive MS.

GETTING THE RIGHT ADVICE
Our research staff are not medical professionals. This page is designed to provide general information. If you have specific health questions, please talk to your health care professional.

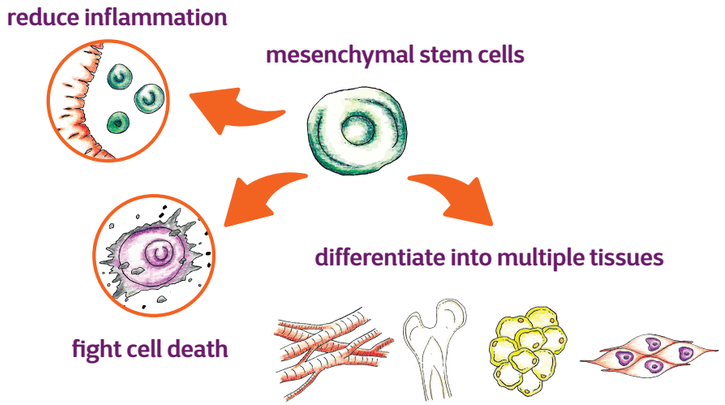
STIMULATION INSTEAD OF REGENERATION

It's the molecules mesenchymal stem cells produce, rather than the cells themselves, which are exciting to MS researchers

MESENCHYMAL STEM CELLS (MSCS) are adult stem cells that can turn into muscle, bone, cartilage and fat. But it's the chemical factors that MSCs release – and the way these affect other cells in the body – that offer the hope of a new treatment for MS.

In mice, these factors have been shown to slow or stop some cells dying and change the way the immune system behaves. MSCs might even be able to promote myelin production.

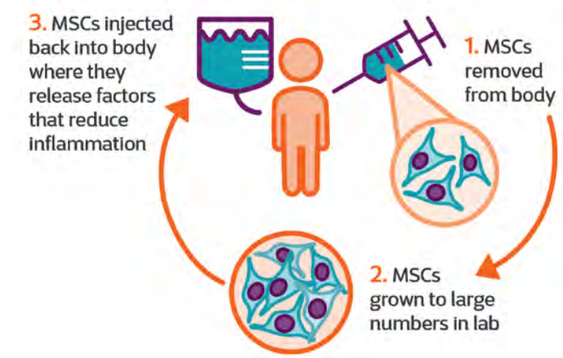
Researchers are now looking at whether they have the same effect in humans.



MSC therapy for MS reaches the clinical trial stage

Preliminary results of an international phase 2 clinical trial are expected later this year

SMALL CLINICAL STUDIES have been investigating the safety of isolating, growing, and re-injecting a person's own MSCs into the blood and spinal cord. The good news is that, so far, only minor side effects have been reported.



An international effort

MESEMS is an international phase 2 clinical trial investigating whether MSC therapy is safe and effective for people with relapsing or progressive MS. Full results are due to be published in 2019.

We funded the UK arm of the trial, called STREAMS, led by Professor Paolo Muraro at Imperial College London.

watch Professor Paolo Muraro talks about his hopes for the STREAMS trial in our latest Meet the Researchers video series **youtube.com/watch?v=I95Br4nnTXI**


MARK LEWIS HAD EXPERIMENTAL MESENCHYMAL STEM CELL THERAPY

In search of a miracle

TV documentary follows one family's hopes as they agree to undergo experimental treatment

LAWYER MARK LEWIS took part in a mesenchymal stem cell therapy trial in Jerusalem late last year, and shared his experiences with Channel 4 in a documentary called "In Search of a Miracle Cure". We caught up with Mark to talk more about his experience.

'I'm not what you would typically think of for a person with MS. I work 12 hour days, six days a week. Although to be fair I then have to spend at least one day in bed.'

An intensive trial

'Last year, my partner Mandy and I travelled to Hadassah University Medical Centre in Jerusalem, and I took part in a trial with mesenchymal stem cells– where the stem cells are injected into the fluid that surrounds your brain and spinal cord.

'The trial was quite intensive. I visited Jerusalem ten times over 15 months, and had five MRIs and psychological testing, and plenty of injections.

'As well as having numerous blood tests and saline drips, I also had two injections of the mesenchymal stem cells into my spine. One of these injections may have been a placebo – I wasn't told. If the first one was then it was a very good placebo! The second spinal injection did nothing, so I hope that wasn't the real thing.'

Symptom improvement

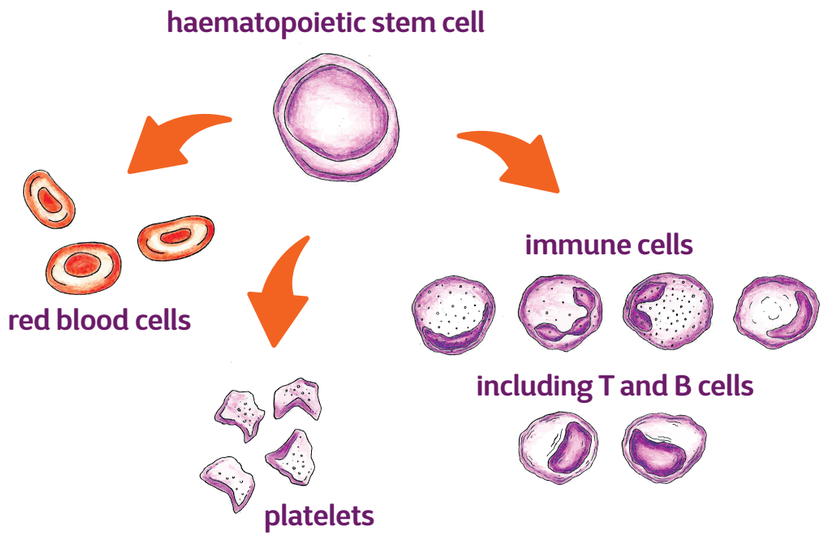
'My MRI scans since have shown some reversal of the myelin damage that occurred previously. After the trial I saw a major improvement, and after my first injection I was already walking. The improvement has stripped back quite a bit since – my mobility didn't stay that good – but my movement and speech have definitely got better. The trial is over now but there will be a follow up, and I think I have a reasonable chance of getting onto it. I'm hopeful.'

HITTING THE RESET BUTTON

Using stem cells to reboot the immune system

HAEMATOPOIETIC STEM CELL therapy (HSCT) aims to stop the damage MS causes by resetting the immune system. It uses chemotherapy to wipe out your old immune system, and relies on the potential of haematopoietic stem cells (HSCs) to regrow a new one.

HSCs are adult stem cells found in the bone marrow. It's here they multiply or become blood cells, including all those that make up the immune system.



Decades in the making

Doctors have been using cell transplantation to treat blood cancer since the 1950s. And in the 1990s, the first transplants were carried out in people with autoimmune diseases. To date, over 2,000 people with an autoimmune condition have had HSCT across Europe. For MS, HSCT is being used to treat highly active forms of the condition at specialist sites in the UK.

HSCT – what actually happens?

HSCT involves a number of steps:

1. Drugs are used to encourage HSCs to move from the bone marrow into the blood. About ten days later, the stem cells are extracted from the blood and frozen for later

2. Chemotherapy is given to wipe out the immune system. Known side effects of chemo include fever, nausea, hair loss, increased risk of infection and infertility

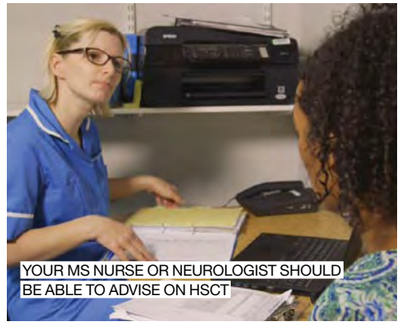
3. The stem cells are defrosted and put back into the blood via a drip. Here they get to work re-building the immune system

4. The person remains in isolation while the stem cells re-build the immune system. This can take between 10-30 days

5. Follow up visits are needed. Short and long-term medication may also be required.

Finding out if HSCT is right for you

HSCT can be life-changing for some, but it can't help everyone



FOR SOME PEOPLE, HSCT can help prevent MS symptoms from progressing, and sometimes even improve them. But HSCT doesn't seem to be effective for all types of MS.

Because the therapy targets the immune system, HSCT typically works best for people with highly active relapsing MS. This means you are either experiencing lots of relapses or you have new lesions showing on an MRI scan. It also seems to work best for people who've had MS for less than ten years and don't have significant disability.

Progressive MS

For progressive MS, we've seen some encouraging results for people treated early on in their condition, and where there's still evidence of inflammation (on an MRI, or through relapses). HSCT has been shown to halt clinical progression in a few people with early secondary progressive MS.

Unfortunately, HSCT has not been as effective for people with progressive MS who no longer show signs of inflammation and who have high levels of disability. Experts think this is because at this later stage of the condition, any worsening of disability is driven by nerve cells dying rather than immune attacks. If you already have a lot of nerve damage, chemotherapy can do more harm than good.

Side Effects

HSCT comes with short and long-term risks and complications.

These include:

- An increased, long-term risk of developing infections
- An increased risk of developing cancer and autoimmune conditions
- A mortality risk of around 1.3%, but this is decreasing

Unanswered questions for HSCT in MS

TRIALS OF HSCT FOR MS have tested different levels of chemotherapy and involved people with both relapsing and progressive MS.

The level of chemotherapy used has an impact on how successful the treatment is, but also affects the risks involved in the procedure – more aggressive chemotherapy carries higher risks and has more severe side effects. Clinics in the UK tend to use low intensity (non-myeloablative) chemotherapy, but there isn't yet a consensus on which chemotherapy option would be the best approach to treating MS.

The recent international MIST trial showed HSCT using non-myeloablative chemotherapy was able to help people still experiencing relapses despite taking other disease modifying therapies (DMTs), including fingolimod (Gilenya) and natalizumab (Tysabri).

We're now pushing for a definitive clinical trial comparing HSCT with the more aggressive DMTs, such as alemtuzumab (Lemtrada). If it's shown that HSCT is more effective than the strongest DMTs, the treatment would be more likely to become widely available on the NHS.

You can read more about HSCT trials at **mssociety.org.uk/hsct-clinical-trials**

ACCESSING HSCT

There are different routes to accessing HSCT for people in the UK, including through the NHS. We're working to help people with MS understand these routes and to get access to the right treatment for them

Through the NHS

The situation around accessing HSCT is ever-changing but **you can access HSCT on the NHS**. At the moment, it's only considered as a third line treatment for people in England who meet very specific medical criteria, including evidence of inflammation, such as active lesions on recent MRI scans. These criteria are aligned with the European Group for Blood and Marrow Transplantation (EBMT) guidelines for HSCT. A third line treatment means that HSCT will only be considered for people who tried two different DMTs (including one of the more aggressive DMTs), which have failed to control their MS.

For people in the other nations who are eligible, you can be referred to England for HSCT, but you may need to speak with your neurologist about an individual funding request for the treatment.

The main sites offering HSCT for MS in the UK are Sheffield and London (King's College and Imperial College). The criteria vary slightly between sites. So it's worth checking with your neurologist about which site would be best suited for your situation.

Going private

HSCT can be accessed privately at the centres in Sheffield and London. Again, the eligibility criteria varies between centres.

Going abroad

If you're not eligible for HSCT on the NHS, it's possible to get the treatment abroad. There are sites in Mexico, Russia and India that we know offer the treatment. This option is very expensive, and not always safe, as not all clinics work to the same safety standards as those in the UK. There is also no guarantee that the treatment will work. We would urge anyone considering going abroad for treatment to first talk their options through with their MS nurse or neurologist.

read BBC reporter Caroline Wyatt has written an honest and insightful blog about her experience of HSCT in Mexico. You can read it here: **http://www.bbc.co.uk/news/resources/idt-sh/caroline_wyatt_multiple_sclerosis**

HSCT access and the MS Society

WE'RE WORKING ALONGSIDE EXPERTS in the field to help ensure people with MS are able to access treatments that are right for them at the right time. This includes HSCT.

- We're currently scoping potential sites of expertise where HSCT could be established
- We've been speaking to the National Institute for Health and Care Excellence (NICE) about when they plan to review HSCT for the NHS
- We're working to clarify the access situation in Northern Ireland, Scotland and Wales

Find out more about HSCT on our website: **mssociety.org.uk/hsct**

A personal choice

There are many factors to consider when deciding whether or not to have HSCT

"HSCT made sense to me"

COLETTE BEECHER WAS DIAGNOSED WITH MS IN JANUARY 2011.

'DESPITE TAKING A DMT, I soon noticed I was falling into a pattern of two relapses a year – that's when I heard about HSCT. I ticked all the boxes.

When I went on treatment before, I'd agonised over my options – but HSCT made perfect sense to me.

I knew the chemotherapy could be tough, but it's a known risk. I knew what to expect and, to me, that was very reassuring.

I was actually well all the way through the treatment. I escaped most possible side effects from the chemotherapy, no nausea, no fatigue. I know that's not everyone's experience so I feel very lucky.

I'm now two years post treatment and my MRI confirmed there have been no further signs of active disease since having HSCT. This is what I was hoping for – I'm very thankful.'


STEM CELL HARVEST DAY

"HSCT wasn't the right choice for me"

ANONYMOUS

'I'VE OFFICIALLY HAD MS for four years now, after experiencing my first symptoms six years ago. My symptoms currently include weakness and pain mainly in my right leg, bladder weakness, increasing 'cog-fog' and sensory loss mostly on my left hand side.

I continued to have disease activity after trying two different DMTs, and was told that I would be a candidate for HSCT. I knew this wasn't a decision to be taken lightly. My consultant and I talked through the side effects, including hair loss and increased infection risk, and how I would need time off work (that I couldn't necessarily afford). And that there was any guarantee it would work.

But for me the biggest factor was that there was a 70% chance of becoming infertile. Despite being currently single, I'm a woman in my early 30s and was not willing to take that chance.

Taking all the above into account, I decided to opt with the safer option of Tysabri, and I feel that my condition is thankfully currently stable. I wouldn't rule out HSCT as a future option but it's not right for me at the moment.'

PROFESSOR GAVIN GIOVANNONI, CHAIR OF NEUROLOGY, QUEEN MARY UNIVERSITY OF LONDON

'IF SOMEONE UNDER my care, having tried two treatments one of which was a high efficacy treatment, was still having ongoing disease activity, I'd take them through their options. This includes either another highly effective disease-modifying therapy or HSCT. It's a tricky and ultimately personal decision – my job is to make sure they are aware of the potential risks and benefits of their choice and to manage their expectations.'