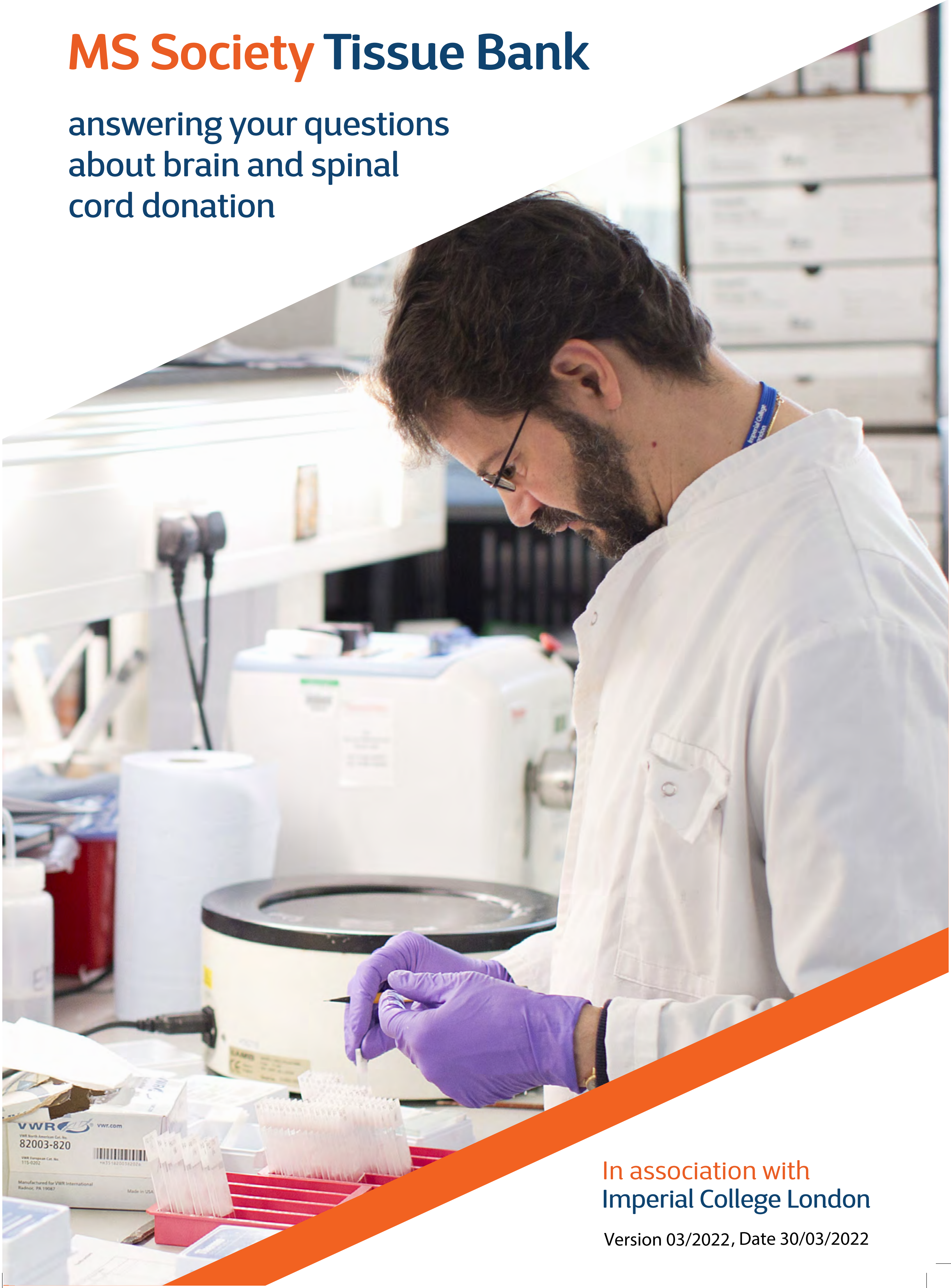
MS Society Tissue Bank

answering your questions about brain and spinal cord donation



In association with
Imperial College London

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MS Society

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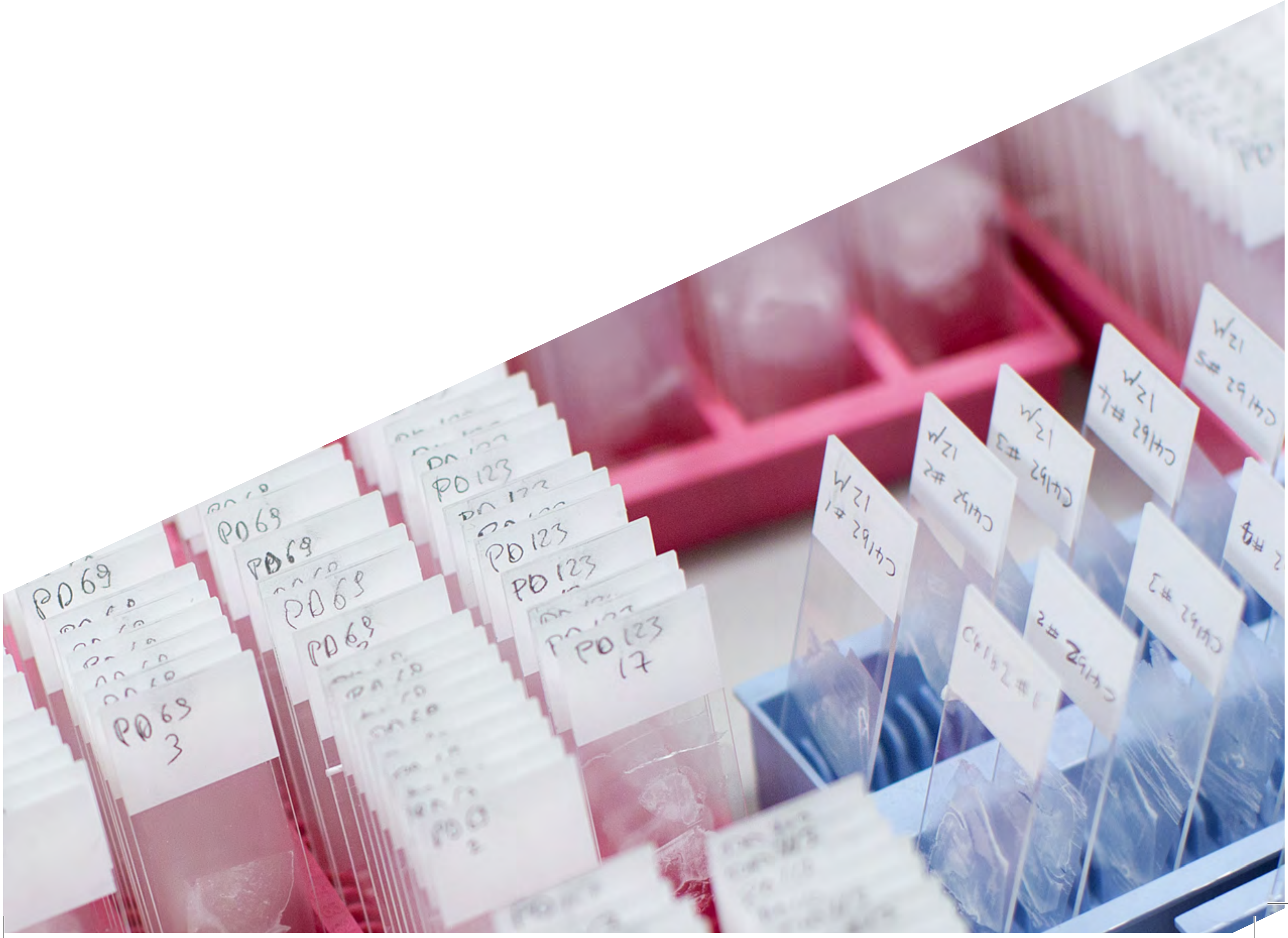



Imperial College
London

Introducing the Tissue Bank

The MS Society Tissue Bank collects precious tissue from people with and without MS who have decided to leave their brain and spinal cord to MS research.

Our Tissue Bank is a vital resource for scientists dedicated to MS research. MS is a uniquely human condition, and to understand its causes and development researchers need to look at how it affects the human brain. This research could lead to discoveries that help us to find a cure and improve life for everyone affected by MS.

The Tissue Bank is funded by the MS Society and based at Imperial College London.

The work of the Tissue Bank is regularly reviewed by an independent panel of scientific experts and people affected by the condition and all our processes have gained approval from the National Research Ethics Service.

This information booklet is designed to answer any questions you may have about brain and spinal cord donation.

If, after reading the booklet, you are interested in joining the donor register, please discuss it with those close to you.

You can find the registration forms on our website or request them by contacting the Tissue Bank directly.

We are happy to answer any questions you may have.

Website
www.imperial.ac.uk/brain-bank

By phone
+44 (0) 20 7594 9734

By email
msbank@imperial.ac.uk

About the tissue we collect

What tissue is collected for research?

MS is a condition that is specific to the brain and spinal cord, so these tissues are of most use to research. The cerebrospinal fluid (CSF) bathes the brain and spinal cord, so the study of CSF may also provide useful information. To explain why the damage is restricted to the brain and spinal cord, scientists may wish to compare this organ with other tissues, for example, muscle. Therefore we routinely remove the following tissues and fluid from our donors:

- the entire brain
- the entire spinal cord
- the whole pituitary gland
- a sample of CSF - the clear, colourless liquid that surrounds the brain and spinal cord
- a small sample of muscle from the back

If a full post mortem is being conducted by the hospital, or on the order of the coroner, we may also collect samples of colon, intestines, spleen, liver, cervical lymph nodes and adrenal gland.

As we learn more about MS and other parts of the body that can be affected, in future we may need to collect small samples of other tissues for research – such as from the gut, or samples of skin tissue.

If this happens, we will always ask your next-of-kin's permission before removing any material in addition to what is listed above.

Can I donate other parts of my body through other donor schemes as well?

Yes, we can work with other UK organ donor schemes for transplantation and research, including the NHS Organ Donor Register.

Just let us know which other donor scheme you are registered with and we'll update your record.

Unfortunately, we cannot work with whole body donation schemes – as these require the whole body including the brain and spinal cord.

I don't have MS. Could my brain still help researchers?

Yes, researchers urgently need brains without MS – also called 'control' brains. Control brains are essential for experiments. Scientists can only work out what is going wrong in MS by comparing control brains with the brains of people with MS.

How brain and spinal cord tissue is used in MS research

Why is tissue needed for MS research?

The symptoms experienced by people living with multiple sclerosis are a result of damage taking place within their brain and spinal cord. Although there are a number of different ways to conduct research on MS, being able to study the very tissue that is damaged in this disease is vital to our developing better treatments.

The MS Society Tissue Bank retrieves and stores tissue bequeathed by registered donors and makes samples of the material available to scientists carrying out research on MS. The donation of tissue is therefore a precious gift that will further our understanding of MS and make an essential contribution to finding a treatment for the disease.

How is tissue made available to researchers?

To help as many research projects as possible, each brain is divided into around 250 samples. These samples are stored safely and securely at the MS Society Tissue Bank.

Scientists from the UK and around the world apply to use the tissue in their research.

We have a panel of scientific experts and people affected by MS who carefully review each application before approving the projects to which we supply tissue.

The researchers we support provide us with a written report so that we can track the outcomes of research carried out using donated tissue.

What type of research might my tissue be used in?

We cannot predict what type of project your tissue will be used for or where the research will be carried out as we support a wide variety of MS research projects that take place all of the world – and one brain or spinal cord may be used in many different projects. The experimental techniques may range from looking at pathology present in the tissue, isolating proteins or DNA to culturing of brain cells and establishing immortalised cell lines.

However, every project we support is ethically and scientifically approved, and will help us better understand and ultimately stop MS.

In addition to research, your tissue may be used for teaching purposes in the training of healthcare professionals, in the UK.

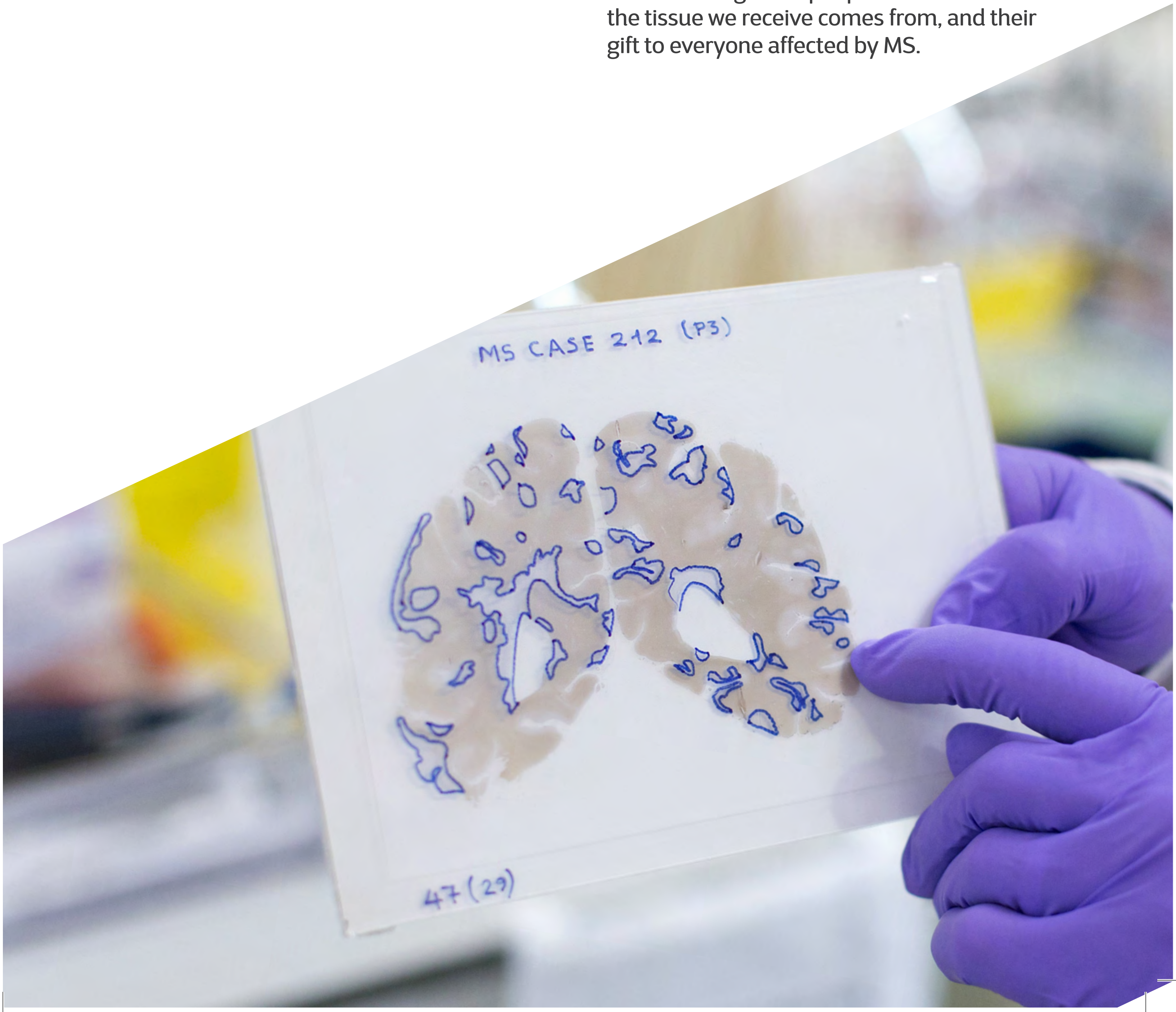
How and where will tissue be stored?

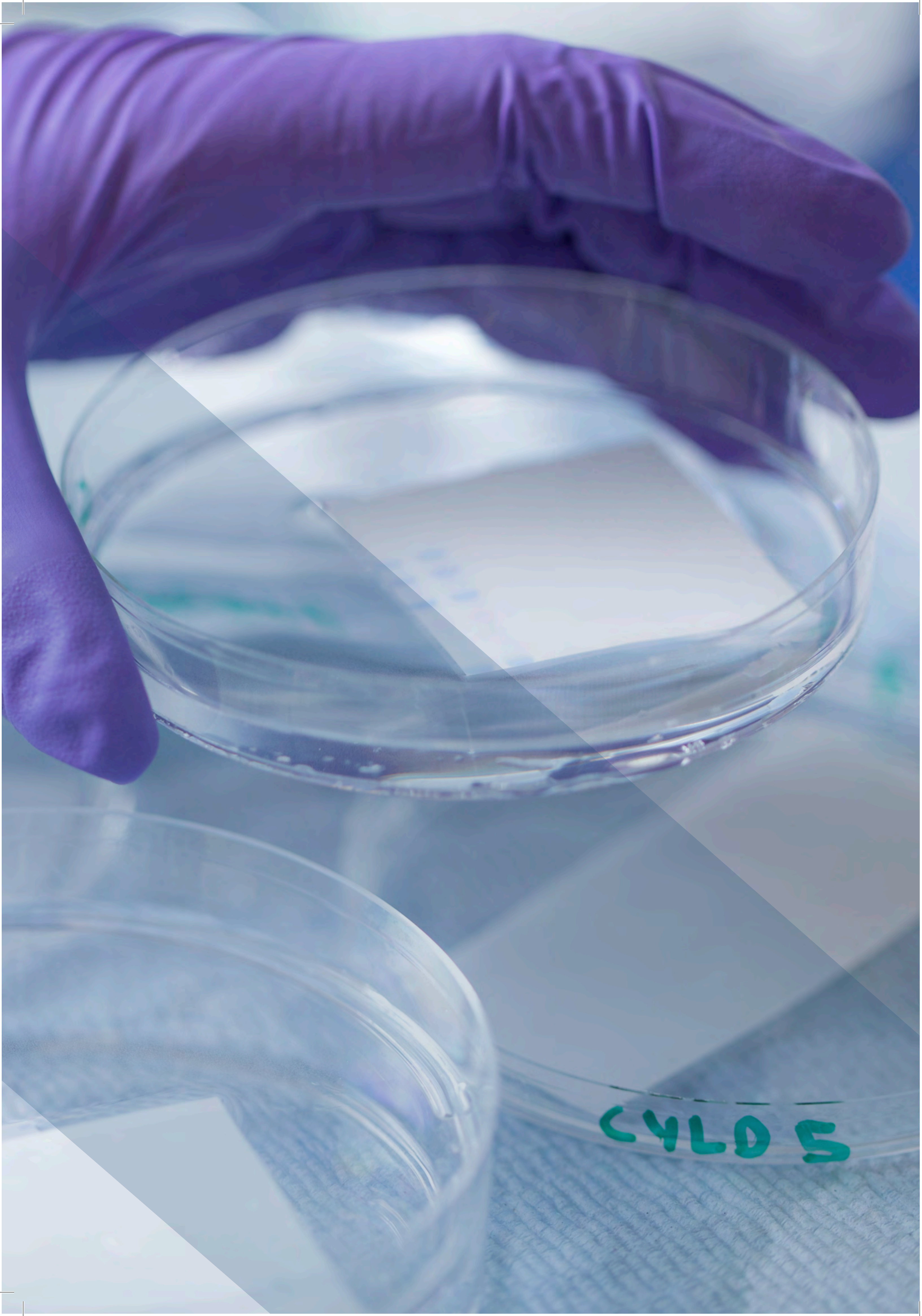
We carefully preserve donated tissue by storing it at the Tissue Bank in Hammersmith Hospital in London, either in formaldehyde (a liquid fixative) or by freezing it at -85 C. This means the tissue can be used for research over several years.

What happens when tissue can no longer be used?

When tissue is no longer suitable for research we carefully dispose of it, after consultation with the MS Society and other appropriate organisations.

All tissue is disposed of in a respectful manner. We never forget the people and families that the tissue we receive comes from, and their gift to everyone affected by MS.

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Becoming a donor

What do I do if I would like to donate my brain and spinal cord?

If you decide that you wish to donate your brain to MS research, please discuss it with your next-of-kin and those close to you.

You can find the registration forms on our website or request them by contacting us directly. Your next-of-kin or a legal representative will also need to complete a form as they will be vital in making sure that we can carry out your wishes.

When we receive your completed forms we will record your details on our secure and confidential system and issue you with an information pack including your donor card.

What can I do to prepare for donation?

- Keep our 24 hour emergency contact number with you at all times – it will be on your donor card along with your personal donor number.
- Make sure your next-of-kin is aware of your wishes and the process of collection. Make sure they know where to find the 24 hour emergency number and have a copy of 'What to do if a donor dies' information sheet.
- Discuss your wishes with key medical professionals, such as your GP, and ask them to update your medical records accordingly.

Will brain and spinal cord donation affect funeral arrangements or having an open casket viewing?

No, brain and spinal cord donation will not delay or interfere with your plans for a funeral, cremation or burial. The brain and spinal cord are removed in a respectful and careful manner that will not affect the appearance of the body.

What if I sign up and then change my mind?

We understand that brain and spinal cord donation is not right for everyone. You are free to change your mind at any time – just contact the tissue bank to let us know. We will then return your signed consent forms and remove your details from our database.

Collecting brain and spinal cord tissue – information for next-of-kin

How quickly does tissue need to be collected?

We aim to collect tissue as quickly as possible. Brain and spinal cord tissues deteriorate very rapidly and 48 hours after death, tissue is no longer suitable for MS research.

What does my next-of-kin need to do when I die?

If a donor has died or is not expected to live much longer, someone must call our emergency number as soon as possible. The number is **07566 950 965**.

We respond within 30 minutes to calls to our emergency number between 9am and 5pm, Monday-Sunday. If we receive their message outside these hours we'll be in touch the first thing the next day. Please do not call the emergency number unless a donor has died or is likely to die. For all other queries about the MS Society Tissue Bank please call **+44 (0) 20 7594 9734.**

What else will my next of kin need to do?

Tissue cannot be removed until we have a signed medical certificate of death, so the next-of-kin will need to request one from the donor's GP or a hospital doctor as soon as possible.

The body also needs to be kept cold to help preserve the tissue. So the body should be transferred as quickly as possible to:

- A funeral director if the death occurred at home or in a care home
- A mortuary if the death occurred in hospital

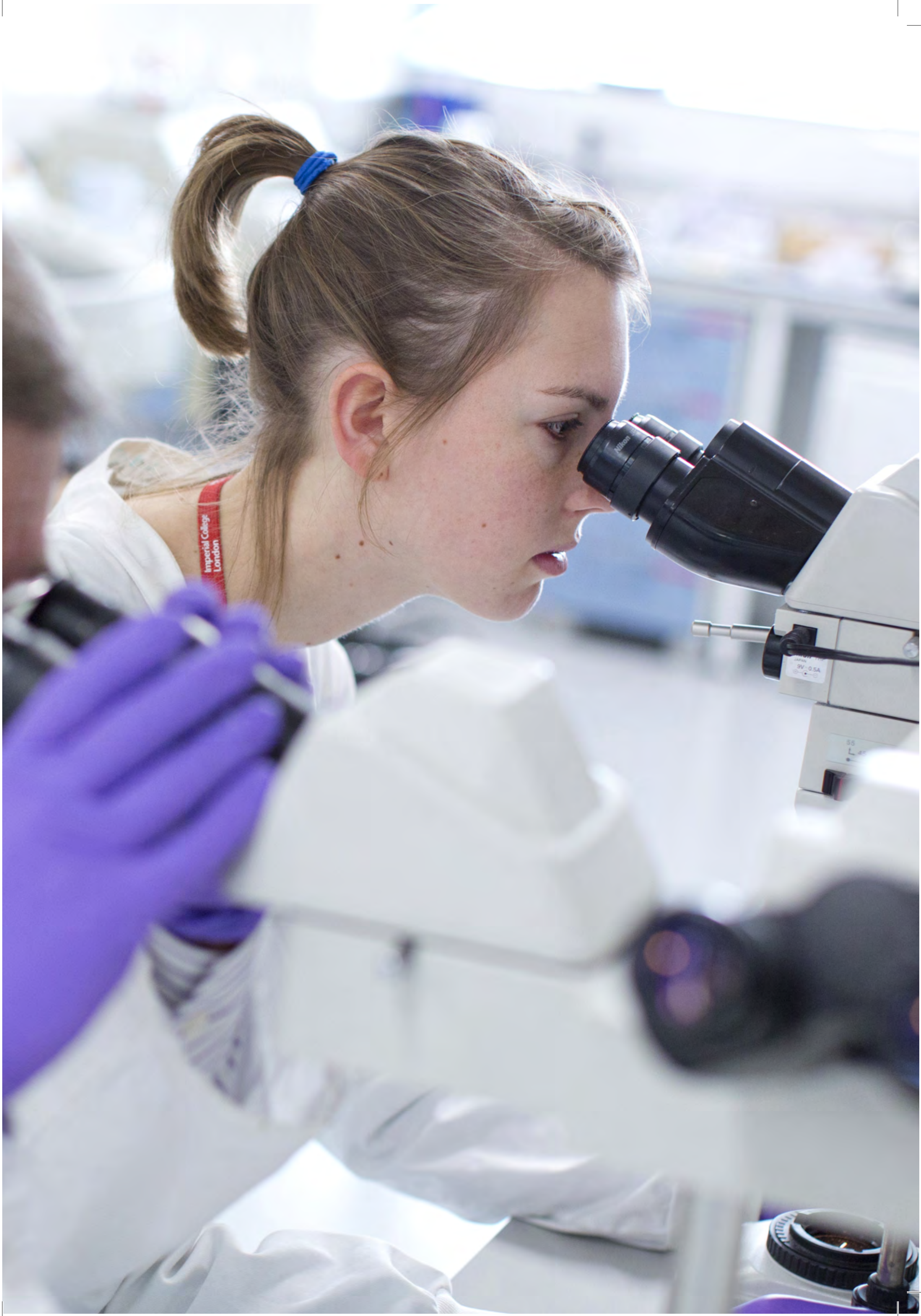
What further help is available for next-of-kin?

We really appreciate their help during this difficult time, and we're committed to doing everything we can to support families through the process.

The MS Society Tissue Bank team will talk the next-of-kin through what they need to do and will work closely with hospitals and undertakers to organise tissue collection as quickly and smoothly as possible.

We have produced an information sheet called 'What to do if a donor dies' to guide people through the process. This is available on the website at **www.imperial.ac.uk/brain-bank** and will be sent to you with your donor card if you register.

After the tissue has been collected we carry out an in-depth examination of the tissue and, if requested, we send a letter to the next-of-kin to explain our findings.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When a donation cannot be fulfilled

How often is brain donation successful?

We try to avoid delays by working closely with families and professionals. But sometimes we are unable to collect and preserve tissue within 48 hours.

On these rare occasions we cannot go ahead with collection because after 48 hours tissue is unfortunately no longer suitable for research.

We are committed to doing absolutely everything we can to honour our donors' wishes.

But it's really important that our donors and their families are aware that there are occasions where we are unable to collect tissue within the crucial 48 hour window.

Why is it sometimes NOT possible to go ahead with the tissue collection?

If a death needs to be referred to the coroner for further investigation, this takes priority and usually means we cannot collect tissue within the 48 hour period.

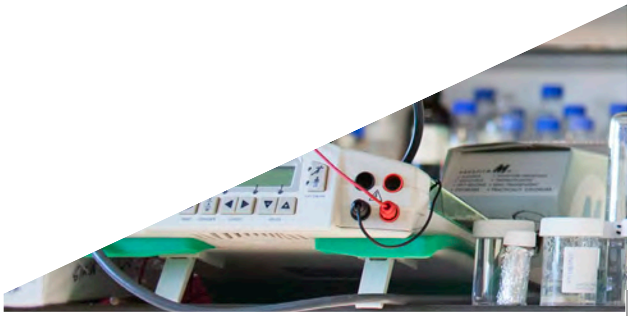
Occasionally a donor may have an infection – such as HIV – which means that it's unsafe to remove the tissue. Conditions such as stroke and cancer also make tissue unsuitable for MS research due to the damage caused to the brain by these conditions.

We are completely reliant on support from health professionals and the NHS to carry out tissue collections, and sometimes it is difficult to get a death certificate signed in time, or to find local mortuary staff able to remove the tissue for us.

These two issues are more of a problem overnight and at weekends when NHS staff are not available. We are working closely with the MS Society and other tissue banks across the UK to solve these problems.

Having a register of people willing to donate their brain and spinal cord tissue supports the future of research into MS, even if it is ultimately not possible to collect the tissue.

The circumstances that may prevent collection do not reduce the value of the intended donation, the spirit in which the gift was made, or the efforts made by the donor's next-of-kin to fulfil the donors' wishes.



Using my personal information

Do you need to know my medical history?

Yes. Having access to detailed information about each donor's medical history means that researchers can match up specific symptoms with the changes they see in the brain.

When you join the donor register we request permission to access your medical records and ask you to fill in a detailed questionnaire. This gives us vital information about your symptoms, lifestyle, and medications.

This information is kept strictly confidential and is completely anonymised before it is shared with researchers.

In exceptional circumstances when we can't access the relevant information from your medical records we may approach your next-of-kin to get this information.

Using your tissue in research studies, such as genetic analysis, may generate information relevant to your relatives. If it does we will contact your next-of-kin and can help arrange genetic counselling.

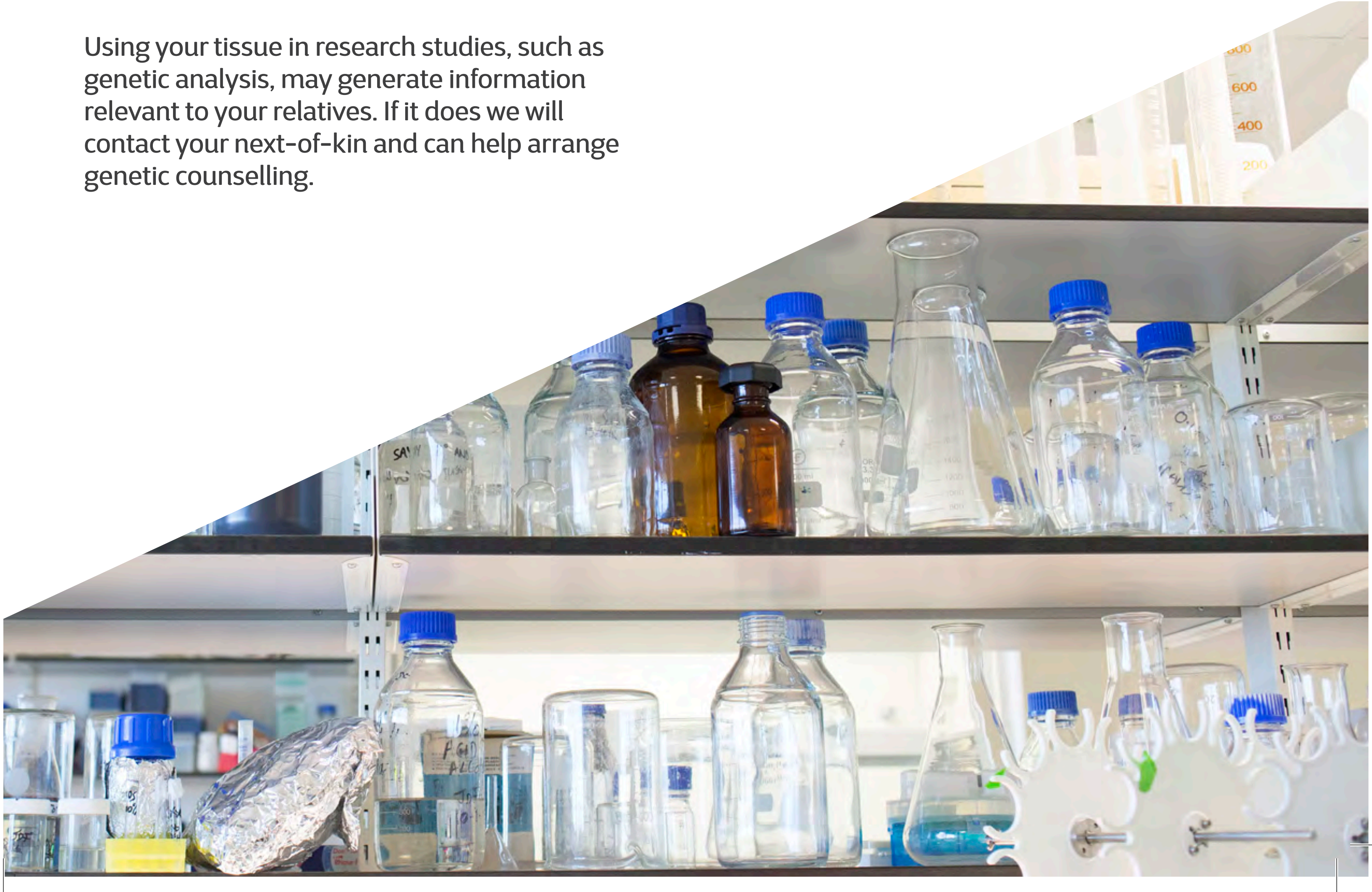
Please note that on some occasions GPs will not be able to forward the information we supply to relatives as they may not have the necessary contact details for your next-of-kin.

Will my personal details and medical records be kept confidential?

Yes. All registration forms and associated paperwork are stored securely and remain strictly confidential.

When a brain is donated, each donor is given a unique identification code and all personal information is removed.

Personal details are never shared with anyone outside of the MS Society Tissue Bank – including researchers.



We hope that this booklet will have helped you make your decision about brain and spinal cord donation.

If you would like to request a donor registration park or have any questions about the MS Society Tissue Bank, please contact them directly at:

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London W12 0NN

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www.imperial.ac.uk/brain-bank/