

Bank perspective:

Ville Pitkaaho, tissue bank research nurse

Ville joined us in 2015 having worked in intensive care and on NHS clinical trials.



What's a typical day for you?

I spend most of my time liaising with donors, their families and health care professionals such as MS nurses. But when my pager goes off – meaning we've been informed of a donor's death – retrieving the tissue has to be my top priority. With a 48-hour time limit this can make for some busy days! After tissue arrives our team prepare and preserve it for storage so that it's ready when researchers need it.

What do you like most about your role?

Organising tissue donations can get really complex at times and I have to persuade different professionals to work together quickly. But it is extremely rewarding once everything has been put in place and I feel very privileged to be able to help fulfil the last wishes of our donors.

What would you like to say to donors?

I'm here to help so please feel free to get in touch if you have any questions about our work or tissue donation (details below). It's really helpful to us if you can tell friends about the tissue bank, and encourage them to consider registering as a donor. I would also encourage everyone to sign up to the MS Register.

UK MS Society Tissue Bank fact file

Over **700** people to date have donated their tissue and a further **4,000** people have registered to donate tissue after their death.

Since 1998, we've sent out over **20,000 individual tissue samples**, supporting **400 research projects** around the world. This has significantly advanced our understanding of MS, and has led to the publication of over **200 scientific papers**.

How to get in touch

What to do if your details change: If any details, such as your name, address, telephone number or your GP change, please ring our office number on **020 7594 9734** to let us know. Also, please update any change of details for your next-of-kin.

Emergencies: If you need an immediate response from the Tissue Bank or need to report the death of a donor please call our 24-hour Emergency Donor Line on **07659 132 045**. Please note if a call is received after 5pm we will respond the following morning.

Donor registration: If you would like to register onto our donor scheme please call **020 7594 9734** or email ukmstissuebank@imperial.ac.uk for a free registration pack.

The Bank Statement



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A letter from Richard Reynolds



Welcome to the latest issue of the Bank Statement, the newsletter from the UK MS Society Tissue Bank at Imperial College London.

Over the last 16 years the MS tissue bank has become a vital part of the international effort to stop MS – and its success is largely down to you, people affected by MS. Your support has enabled us to build a world leading facility that provides samples of donated MS brain tissue to important research projects in the UK and around the world: again we want to say a big THANK YOU!

The tissue samples that we have provided to researchers over this last year have played a major role in advancing our understanding of how MS affects the brain and in the development of new treatments. In particular, the tissue bank has contributed to projects supported by the Progressive MS Alliance, a collaboration between MS charities worldwide that aims to fund the development of new treatments to stop progressive MS.

Inside this issue, we share with you some of the latest research discoveries that have been

made possible by donated tissues. This year we have also linked up with the MS Society funded MS Register for the first time, speaking to Rod Middleton about this innovative research project as well as future collaborations.

We would also like to remind all of our donors about the changes that took place last year to the 24 hour Emergency Donor Line. The same number will continue to be in operation 24 hours a day and we still need to be informed of the death of a donor as soon as possible. Calls made between 5pm and 9am will be answered by an operator who will record your message and our coordinator will be in touch first thing the next day.

I hope that you enjoy reading about some of the exciting research being carried out using donated MS tissues and the latest developments in the tissue bank. Thank you again for making such a valuable and vital gift to a future without MS.

Professor Richard Reynolds, Director,
UK MS Society Tissue Bank

IN ASSOCIATION WITH **Imperial College London**

Spotlight on research

We hear about three exciting projects that have been supported by the Bank

Identifying biomarkers that predict progression in MS

Led by Roberta Magliozzi, Richard Reynolds and Massimiliano Calabrese at the University of Verona, Italy and Imperial College London, UK.

What is the study about?

The brain is surrounded by a protective layer known as the meninges. This appears to become inflamed when people transition from relapsing to progressive MS. This inflammation traps immune cells in the meninges, which could contribute to nerve damage in MS.

This study used samples provided by the tissue bank to show that immune cells trapped in the meninges produce a range of pro-inflammatory molecules, which are linked to increased nerve damage as well as more rapid progression.

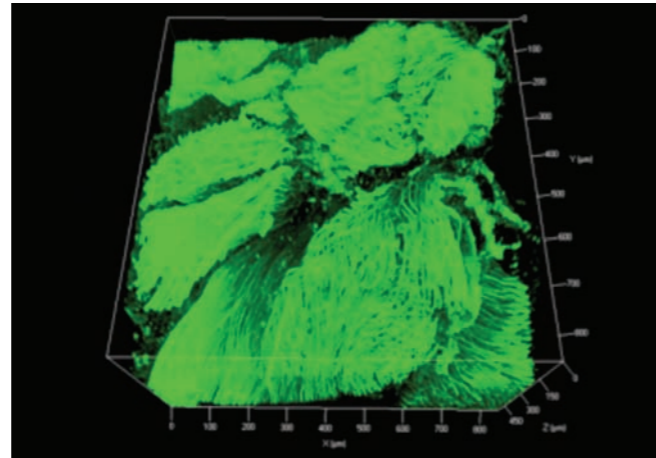


How will it help people with MS?

These molecules could be used as biomarkers to help us better predict progression in MS, giving people with MS greater certainty in their lives. It could also help people to make more informed choices when deciding to take more or less aggressive treatments.

CLARITY for MS

Led by Alan Liu at St Mary's Hospital, Paddington.



What is the study about?

CLARITY is a new technique that allows researchers to look at large sections of tissue in three dimensions. It has successfully been used to visualise the damage seen in autism, Alzheimer's disease and Parkinson's disease.

Using samples provided by the tissue bank, researchers have for the first time created a three-dimensional representation of the spinal cord nerves of a person with MS.

How will it help people with MS?

This study showed that this technique can be used to study damage to the central nervous system seen in MS.

Researchers will be able to use CLARITY to study areas of myelin damage (lesions) in more detail, improving our understanding of how nerve damage occurs in MS.

"The tissue samples we have provided over this last year have played a major role in advancing our understanding of how MS affects the brain and in the development of new treatments."

Richard Reynolds, Director of the Tissue Bank

Understanding the epigenetic changes in MS

Led by Lou Brundin and Maja Jagodic at the Karolinska Institute, Sweden.

What is the study about?

Epigenetics is the way in which genetic information is packaged. Unlike genetic information, which is the same in every cell in the body, epigenetic information can vary depending on the type of cell, as well as in response to changes in the cell's environment. Altering a cell's epigenetic information can affect the way it behaves.

In MS, tissue in the brain and spinal cord becomes inflamed. There is evidence that inflammation may affect cells in the central nervous system by altering their epigenetic information. This project will use samples from the tissue bank to investigate these changes and see if they contribute to the nerve damage seen in MS.

How will it help people with MS?

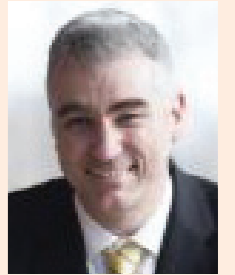
Understanding the mechanisms behind MS progression and how nerves are damaged is essential to the development of new treatments.



Researcher perspective:

the MS Register

Rod Middleton, project manager of the MS Register, tells us about the Register and how it can work with the MS Tissue Bank.



What is the MS Register?

The MS Register aims to build a complete picture of what it means to live with MS in the UK today. We do this by asking people with MS to share their experiences of living with MS. At certain NHS sites, this information can also be linked to people's medical records if they want.

Why is the MS Register so important?

There's a lot of important information that researchers don't have, from how many people are living with MS to what medications and support is being offered in different parts of the country. The data we collect is vital evidence for MS research and in campaigning for better services and support.

How can the Tissue Bank and the Register work together?

Firstly, we are both there to support MS research. In the future I think it would be great if we could link data from people who have signed up to both the Register and the Tissue Bank to build an even more complete picture of living with MS.

How can people sign up?

You can register with your email address on our website <https://www.ukmsregister.org> and then start taking part in our surveys.

If you live near one of our contributing NHS sites, then ask your neurologist or MS nurse about signing up (you can find more information about which hospitals are currently taking part on our website).