

# New era for DNA Bank: beyond genetic research

**Our UK MND DNA Bank was set up in 2003 to find out more about the causes of MND, using DNA from donated samples.**

**Now, thanks to exciting new developments in technology, the samples will soon be used in research that would have been deemed science fiction a decade ago.**

MND is thought to be caused by a combination of subtle genetic, lifestyle and environmental factors. The UK MND DNA Bank was designed to help identify the genetic factors involved in the disease by studying the DNA (or genetic material) of people with MND.

The DNA Bank consists of over 3,000 samples, which were donated from people with MND, their family members and healthy participants (often from a partner or spouse of someone with MND. These act as 'controls' in research studies).

Together with the accompanying, anonymised information on the participants, these have been used to create an important resource of DNA samples and lymphoblastoid cell lines (white blood cells) for MND researchers to use.

#### **Exciting changes**

Originally, we collected two blood samples. One was used to extract DNA, which is now stored at the University of Manchester. The second blood sample was sent to Public Health England in Wiltshire, to create an

everlasting supply of DNA by storing the white blood cells from the sample.

Today, MND researchers are just as interested in the white blood cells as they are the DNA. This is because, thanks to advances in technology, these white blood cells can be used to



create cell models of MND. White blood cells can be converted into 'induced pluripotent stem cells', which in turn can be turned into motor neurones.

Creating motor neurones from blood cells was unimaginable when the UK MND DNA Bank was first created. Now, these models will be used to further our understanding of MND in the lab. The samples would not be given to patients.

### Making great strides

People living with MND, and everyone who cares for them, are at the heart of everything we do. We know that investing in research is important to you. This is why we have now agreed to researchers using the samples in wider MND research studies (rather than just genetic research) to help achieve our vision of a world free from MND.

Dr Belinda Cupid, Head of Research at the Association, leads on the project. She said: "We've made great strides in discovering the genes that contribute to MND. There's more to do, and DNA in the UK MND DNA Bank will continue to be an important resource.

"However, the next step is to understand why the genetic damage or variations cause motor neurones to die. This means looking at these genes within cells, ideally motor neurones. It is a significant and important step forward that we can use the cells from the DNA Bank for this too."

Dr Colin Fenwick, who has MND, donated a sample to the bank in 2011. He said: "I'm obviously very pleased that the MND Association is widening the type of research that can access samples from the DNA Bank. In the last few years advances in analytical technology have made it possible



*Dr Colin Fenwick and his wife, Alison*

to search for clues in areas that were little more than science fiction only a decade ago. By opening the DNA Bank to these exciting new areas of research, the Association is increasing the likelihood that a breakthrough will be made sooner rather than later."

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Colin's wife, Alison, also gave a sample. She said: "If the DNA Bank can give more information to increase our understanding, and perhaps one day to help in the development of a treatment for MND, then I am very proud to contribute. I hope that this is one small positive thing that can come out of Colin having this awful condition."

### Withdrawing a sample

We have made the decision to allow researchers to use the samples more widely, because we believe that those people who donated a sample would want to invest in this area of research.

However, we recognise that some people may not wish for their samples to be used outside of genetic research. If you would **not** like your sample to be used in this way, or you would like more information, please contact the Research Development Team on 01604 611880 or [research@mndassociation.org](mailto:research@mndassociation.org).

### Endorsing our plans

We act as the custodian of the DNA Bank, maintaining the balance of respecting the wishes of those that took part and ensuring the samples are used as widely as possible to advance MND research.

We have approved over 20 projects using samples from the DNA Bank. Examples of the types of research involved are available on our website: [www.mndassociation.org/mydnabanksample](http://www.mndassociation.org/mydnabanksample). All applications from scientists wishing to use the samples are reviewed by our Biomedical Research Advisory Panel, to ensure the research is feasible and will benefit MND research.

When it emerged that white blood cells could be used for wider MND research studies we sought advice from a number of people on how we should proceed. Our Board of Trustees and our Biomedical Research Advisory Panel, both of which include people affected by MND, endorsed the plans as a positive step forward for MND research.

We also explained our plans to an independent research ethics committee, representing the interests of people with MND in an objective way. They have also approved the use of the samples for wider research. We agreed with the ethics committee, that we would explain our exciting plans as widely as possible, giving those who donated samples the opportunity to withdraw from this new research if they wish.

**Read more on our MND Research blog ([www.mndresearch.wordpress.com](http://www.mndresearch.wordpress.com)) or by contacting the Research Development Team for paper articles.**

### Find out more:

You can find out more about the DNA Bank, current research projects using the samples and more in our **Research Information Sheet J: 'What happened to my DNA bank sample?'**

This can be downloaded from [www.mndassociation.org/researchsheets](http://www.mndassociation.org/researchsheets) or ordered from MND Connect. Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) Telephone: **08457 626262**