

The brains behind MS research



Tissue donation helps pave the way to a cure.

by Aviva Patz

Elizabeth (Liz) Bebo was diagnosed with multiple sclerosis in her mid-30s. “After learning about the opportunity to donate her brain, she became passionate about the idea that her donation could contribute to better treatments and even a cure for MS,” says her son, Bruce Bebo, PhD, executive vice president for research at the National Multiple Sclerosis Society.

“She was quite committed to making this donation,” Bebo adds. “As she moved during her life, she was diligent about updating her contact information so that her donation would be made. She made sure her family knew how much this meant to her and there was no resistance from her loved ones — we all wanted to honor her wishes.”



The National Multiple Sclerosis Brain Bank could help facilitate faster, more efficient clinical trials, which can lead to better treatments. Photo: iStock

When Elizabeth Bebo died in 2018 at age 75, her brain went to an MS brain bank to become one of many ciphers ready to help finally crack the MS code.

“You cannot cure MS without studying MS in the human body,” says Bebo, whose mother’s journey inspired his work in MS research and led to his career with the Society. “Studying animal models in a laboratory gives us clues on what to look for, but real progress toward better treatments and cures for MS will only come from studying people with MS and their central nervous system tissue [brain, spinal cord, and eyes].”

Philip DeJager, MD, PhD, chief of neurology at Columbia University and a principal investigator with the National Multiple Sclerosis Brain Bank, notes the difficulty managing MS once there is brain atrophy. “This is where we need to do more work,” DeJager said in an interview with the Society at the 2023 Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) conference in San Diego. “But the tools are here. [The brain bank] will help accelerate innovation in the future.”

Neuroradiologist and clinician scientist Daniel Reich, MD, PhD, is another principal investigator involved in the brain bank who is helping to make this vital information available to the scientific community. “This type of tissue from people who lived with MS for years is absolutely critical for us to understand what is driving the disease and what is driving progression,” says Reich, a senior investigator at the National Institutes of Health. “We’re hoping to build a bridge between the kind of data we collect from people living with MS and what we can look at with the tissue — and that link has been missing.”

Read on to learn how the new National Multiple Sclerosis Brain Bank, established in 2020, will be a game changer in the fight against MS.

About the National Multiple Sclerosis Brain Bank

The National Multiple Sclerosis Brain Bank is a resource and repository for human specimens — brain, spinal cord, optic nerve and related tissue — along with detailed medical information from people with and without MS. It’s a collaboration between investigators at Columbia University, the National Institutes of Health/National Institute of Neurological Disorders and Stroke, and the Yale School of Medicine, and is funded by the Society.

Types of research being done

The brain bank’s mission is to collect the tissue and make it available for study of the

disease's pathology — its nature, and cause and effects on the brain. Reich's work involves using MRI to inform the interpretation of cutting-edge pathology; for example, looking at genes that are active in each cell type, the proteins they're making and using, how one cell talks to the next cell, and how it all fits together to drive progression and neurodegeneration. "We're finding new methods to link the data we collect over time from people who live with MS to be able to interpret that data in light of what's present in the tissue," Reich says.

Claire S. Riley, MD, the Karen L. K. Miller associate professor of neurology at the Columbia University Medical Center, uses tissue to study aging in MS, specifically cognition. There is often a disconnect between the disease burden on MRI and the clinical symptoms. For example, in her clinical practice, she'll see some people with a lot of disease activity who are minimally affected and others with few MRI-detected brain lesions who become very disabled. "I have to believe there's something about the pathology we're not picking up from the MRI that explains that paradox," Riley says.

The brain bank also could revolutionize MS studies, such as identifying biomarkers, or predictors that could be detected with MRI or a blood test. "Helping to correlate biomarkers with the real pathology can facilitate faster, more efficient clinical trials, which can lead to better treatments," Riley explains. For example, when following people with progressive MS, symptoms can take a long time to manifest — a study might last three to four years with hundreds of patients. "But if you could be certain that a biomarker was associated with progression, then you could design a much shorter study with fewer patients," Riley says. "I would love to see very rapid discovery of treatments facilitated by this improvement in clinical trial technique because we do so much with MRI, and being able to link it to pathology is really powerful."

How it works

The brain bank's work starts with collecting information from people living with MS who intend to donate their tissue. "We get not just their type of MS — relapsing-remitting or progressive — but details about how the disease is impacting them," Riley explains, including their symptoms, treatments and disease course to help scientists make sense of what they're looking at in the tissue.

How to become a donor

To become a tissue donor, visit the [National Multiple Sclerosis Brain Bank](#). The brain bank welcomes specimens from people with and without MS. If you have MS, you'll be invited to enroll in a prospective study to learn about the course of your disease and symptoms related to MS as well as your course of treatment. You'll also be invited to share MRI data and visit the Columbia MS Center occasionally for an in-person visit if possible.

Once the brain bank receives a specimen — it arrives in a special container via FedEx — the

team divides the brain into two hemispheres, explains Riley, who is also Columbia's Multiple Sclerosis Center medical director. Half of the specimen gets preserved in a formalin solution and shipped overnight to Reich at the National Institutes of Health for detailed MRI scans. The other half gets dissected at Columbia, with alternating slabs being preserved or frozen. Any preserved samples with "visually apparent lesions" go to the team headed by David Pitt, MD, at Yale, where they're sectioned, stained and digitized, then shipped back to Columbia to be digitized and entered into a searchable database.

Researchers can fill out a form online to request "this kind of a lesion from that kind of a patient," Riley explains, and the brain bank will send corresponding digital slides or physical samples of pathologic material. This is a resource for the global research community.

Why it's important

While researchers studying cancer can examine biopsies of diseased tissue, "it's rare to biopsy the brains of people living with MS," Riley notes. So, the brain bank provides a piece of the MS puzzle that has thus far been missing.

"We must learn the cellular and molecular mechanisms driving the loss of nerve cells in the brain and spinal cord," Reich says. "And what is the capacity of the central nervous system for repair, so we can enhance that therapeutically? Those are the open questions," he says, adding, "We've become good at stopping new inflammation but we're still feeling our way in the dark in our understanding of what drives the slow loss of nerve cells and how we can repair them. The way we've designed the brain bank should help us answer those questions."

Why it's unique

The brain bank is unique in its lifecycle approach. "We have people volunteering to donate their organs," Reich explains, "but while they're living, we can collect the data we need to make the best use of that tissue when the time comes." Advances in technology, including data collection and high-resolution imaging, will help optimize and sync that information to uncover new treatments — and hopefully someday, a cure. "The brain bank is a place where researchers can come together and not just request tissue but contribute to the community of ideas that will be critical for answering the questions we must answer in order to stop this disease."

And people like Elizabeth Bebo will have helped make it possible.

Aviva Patz is a writer in Montclair, New Jersey.

Learn more about the [National Multiple Sclerosis Brain Bank](#).

Find details about how to [donate to brain and other tissues banks](#).