

# Accelerated Cure Project for MS

# July 2017



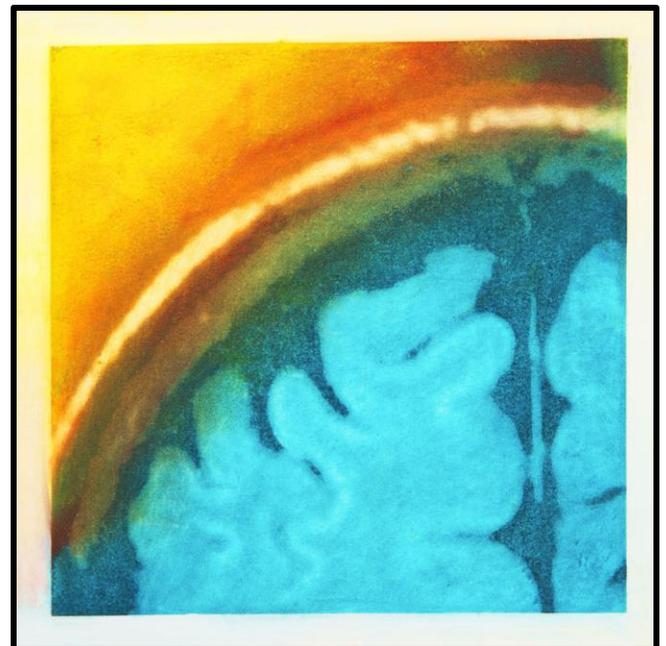
for multiple

sclerosis  
*Accelerating research towards a  
cure for multiple sclerosis*

## Why Brain Donation?

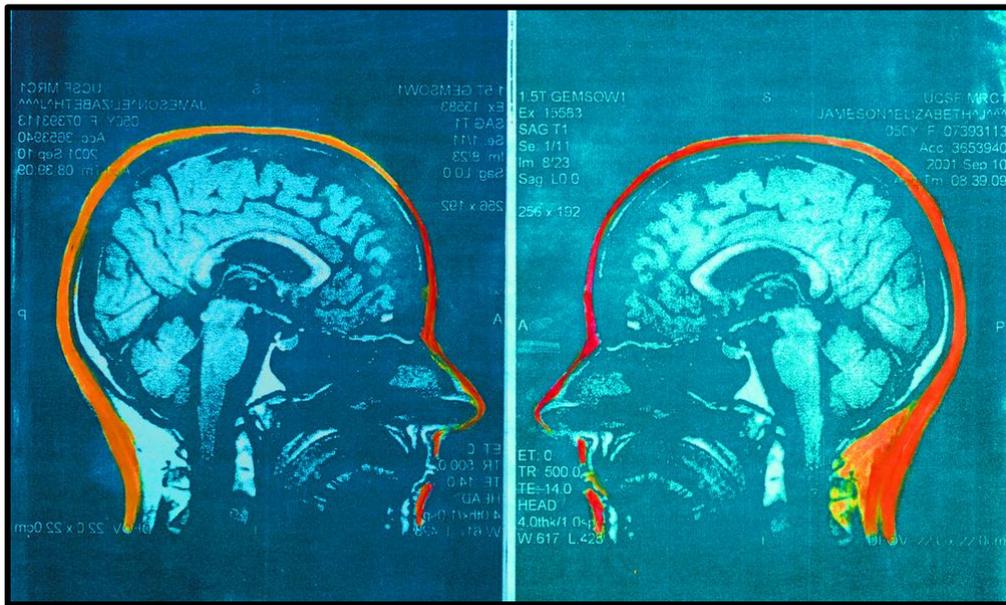
Participating in research in all stages of life is important. Behind every medical advance there is a team of researchers and a group of volunteers that worked together. Participating in a clinical study, either as a patient or as a healthy control, helps researchers to learn more about diseases and how to better treat them. It's also possible to make a significant posthumous contribution to research.

Disorders of the brain affect millions of children and adults, dramatically altering their lives and those of their families. The brain is a complex organ and, while researchers have made significant progress in understanding the brain's function, there is still much to be learned. The acquisition of brain tissue following death is very important for research surrounding how to prevent and cure disorders of the brain. Scientists need tissue from individuals with neurological



*Emerging- Elizabeth Jameson  
Coronal view of the neo-cortex  
Solarplate Etching on Paper*

disorders, as well as healthy individuals, so that they can better understand the difference between the two. Studies using post mortem tissue are the most promising, and some cannot be conducted without this tissue. Specifically, multiple sclerosis research is best conducted using human tissue. Because MS affects the brain and spinal cord, these studies can only be conducted using brain and spinal cord tissue that is collected after death. One could argue that any lack of progress in this area of research may be due to the lack of availability of post mortem tissue. People living with MS may hold the key to curing this disease and a post mortem tissue donation could make a significant difference.

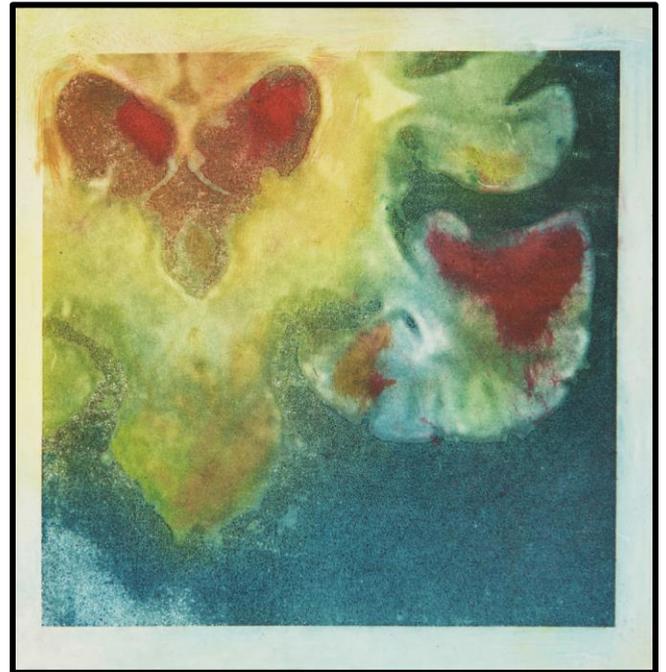


*Conversations with Myself- Elizabeth Jameson*  
*Sagittal view of the artist's brain*  
*Solarplate Etching and Pastel on Paper*

A brain donation is a valuable gift. One donated brain can provide tissue for hundreds of independent research studies. Discoveries made possible by tissue donation can have a lasting impact and provide hope to families affected by brain disease. People of all ages, regardless of previous medical conditions, should consider tissue donation for research. The decision to donate your brain to science can be difficult or painful to think about. Some see tissue donation after

death as a way of gaining something positive from illness by helping others with the same condition. Individuals with inherited disorders may see it as a way to help researchers find new ways of preventing or treating the disease so that the next generation may be spared.

Donated post mortem tissue is made available to qualified researchers through resources called brain or tissue banks, which are laboratories where tissue specimens are stored for later use. There are brain banks worldwide that collect central nervous system tissue from various neurological conditions. Many brain banks operate as a part of a larger consortium that maintain inventories of combined samples and offer a centralized portal for tissue requests from researchers. The NIH Neurobiobank is one such consortium that is supported by the National Institutes of Health (NIH). The NIH Neurobiobank coordinates a network of brain banks in the United States. With this oversight, brain tissue is collected and stored according to the highest standards and the networking of sites makes it possible for the tissue to be made available to the greatest number of researchers. The NIH Neurobiobank also ensures the privacy and wishes of donors. The [NIH Neurobiobank website](#) has answers to questions about brain donation, links to brain banks across the country, and information on how arrangements are made to donate the brain for research.



*Valentine- Elizabeth Jameson  
Coronal view of the Artist's brain stem, cerebellum, and  
lateral ventricles  
Solarplate Etching on Paper*

The [National MS Society](#) supports two MS tissue banks, the [Human Brain and Spinal Fluid Resource Center](#) and the [Rocky Mountain MS Center Tissue Bank](#). These MS tissue banks store brain and spinal cord tissues, spinal fluid, and other specimens from MS patients. These banks are

also interested in collecting specimens from people who do not have MS, or from family members. The banked tissues are carefully catalogued with information about each person's medical history. For more information on either tissue bank, please follow the links above to the appropriate website.

If you are interested in donating post mortem tissue, planning ahead is essential. Brain tissue must be preserved very soon after the death of the donor. The best way to proceed is to contact the brain bank of your choice in advance and let them know of your wish to become a brain donor. They will provide information that is specific to their site and any necessary paperwork to be completed. It's important to discuss your decision to donate with your family or friends and with your physician so they are aware of your wishes and the notification procedures. Tissue donations need not interfere with funeral arrangements, there is no cost to the donor or the donor's family, and the decision to donate can be changed (arrangements are not binding). Consider whether brain donation is right for you. It can be an opportunity to take part in research that may one day save lives.

*We'd like to thank Elizabeth Jameson for giving us permission to use her artwork in this month's newsletter.*

*Elizabeth was "living the dream" with a young family, practicing as a lawyer in social justice, when she was diagnosed with MS. Elizabeth recently spoke at Ted X Stanford about [Learning to Embrace and Celebrate the Imperfect Body](#). In her powerful story she describes her journey with MS and invites others to join in a conversation about dealing with disability and illness.*

*Her artwork allows her to express her feelings about putting the pieces of her life back together.*