

# Accelerated Cure Project for MS

# July 2017



*Accelerating research towards a cure for multiple sclerosis*

Dear Friends,

As a supporter of Accelerated Cure Project, we know you value the research being done to accelerate cures, treatments, and better diagnoses for people with MS. For many, the commitment to support research isn't limited to their lifetimes. In this newsletter, we explore the sensitive and important topic of research done on tissue collected posthumously and the powerful impact it can have.

Our first article tells you a bit more about the hows and whys of brain donation and the important gift one can make. In the second article, epidemiologist Dr. Farren Briggs discusses three recent papers exploring the life expectancy of people with MS and how in recent years, thanks to medical advances, it has increased significantly.

Our partner spotlight this month is MS Focus, and their many wonderful programs they offer to people with MS and their families.

Make sure to read Laura Kolaczowski's article highlighting ACP's CEO Robert McBurney and how [iConquerMS™](#) is a place where people with MS can shape and drive MS research.

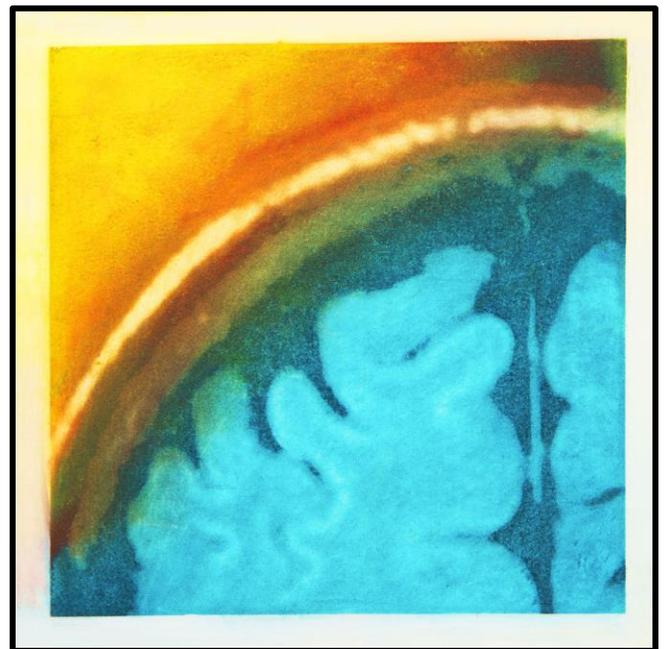
We hope you are enjoying these beautiful days of summer!

The Accelerated Cure Project team

## **Why Brain Donation?**

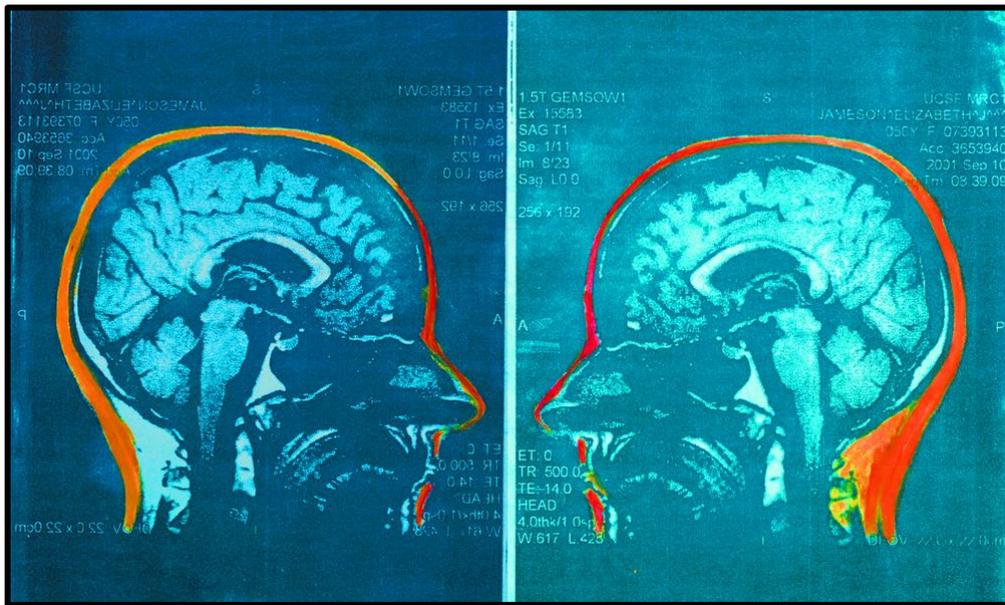
Participating in research in all stages of life is important. Behind every medical advance there is a team of researchers and a group of volunteers that worked together. Participating in a clinical study, either as a patient or as a healthy control, helps researchers to learn more about diseases and 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 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



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

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.



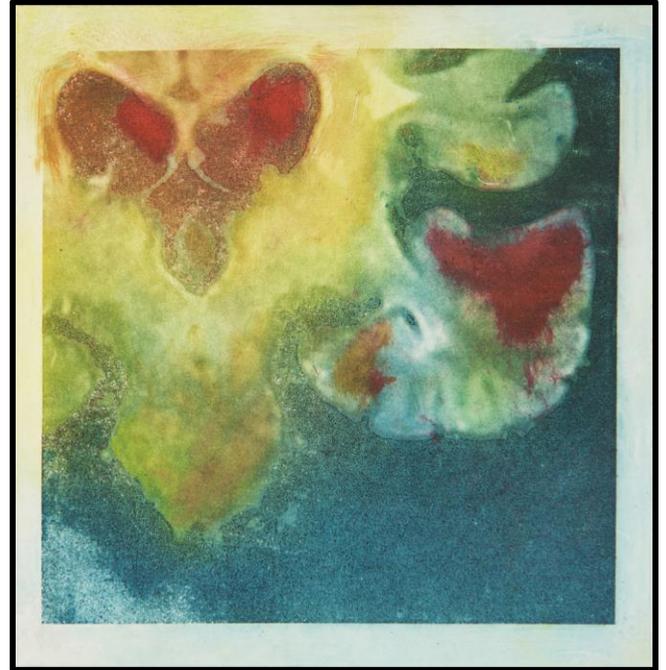
*Conversations with Myself- Elizabeth Jameson*  
*Sagittal view of the artist's brain*  
*Solarplate Etching and Pastel on Paper*

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.

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



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

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.*

## Changes in longevity in persons with MS

By Farren Briggs PhD, ScM

We spend countless hours pondering our time on earth. Hopefully by reflecting on the past, we appreciate the present, and look forward to tomorrow. There are so many questions a person with MS (PwMS) may have for medical professionals, amongst the first questions: “What’s my prognosis?”... “How much time do I have?” Having conversations on one’s mortality is not easy, and challenging, particularly when a disease is highly variable. Nonetheless, these conversations have wonderful silver linings, directing our focus on the present and motivating us to invest in our legacies. For several decades, the life expectancy of PwMS were significantly lower than the general population, however, we have seen great improvements in recent years. This month there were three papers assessing mortality trends in PwMS, demonstrating further improvements<sup>1, 2, 3</sup>.



These studies are unique since they were truly population-based and captured their *source* populations. Whenever conducting a human study, we epidemiologists worry about the representativeness of our study sample and we work through a series of questions and steps when designing our studies and when we interpret our results. For a hypothetical study I may go through these stages: **Question:** What is the population I care to study or who is the *target* population I want my findings to inform/apply to? For me, I care about PwMS. **Question:** What is the *source* population? What population do I have access to? Well, I live in Cleveland, so PwMS in Cleveland. Thus, I may pursue collaborations with neurologists at a local hospital XYZ. My collaborators and I may approach all of the PwMS in their practices, and let’s suppose 50% of the PwMS approached were willing to participate in my study. I conduct my study, I run my statistical models, and generate results. But before I can interpret my results, I work back through these questions.

**Question:** Who was my study sample? Are they representative of all PwMS at hospital XYZ (why

would someone not participate in a study? Are they too busy? Too sick?) **Next Question:** Are PwMS at hospital XYZ representative of all PwMS in Cleveland? (What type of insurance does this hospital accept? What neighborhood is it in? Are there reasons why the population at hospital XYZ might not reflect the rest of Cleveland? Am I capturing only the very sick by using a hospital?)

**Next Question:** How do PwMS in Cleveland compare to PwMS from rest of Ohio, the Northeast USA, the USA, and the world?

Thus, can I connect my *study* sample to my *source* sample and then to my *target* sample. Mind-bender right?! Fortunately, I can account for some of these gaps with statistical approaches, but not all. In the end these questions matter as they determine the validity of my study, and how broadly I can generalize my results.



Well, these three papers did an impressive job of capturing their *source* populations, since their *source* is also their *target* population. They also used data spanning many decades. The **first study** by Burkill et al, and published in *Neurology*<sup>1</sup> used multiple national Swedish registries, which included detailed health information, to identify all Swedish persons with a diagnosis of MS between 1968 and 2012. For each PwMS identified, ten individuals without a diagnosis of MS but with the same age, gender, county of residence were also selected. The study was comprised of 29,617 PwMS and 296,164 controls. There were many findings, but the most interesting was the change in mortality over time. There was a 3.5 fold reduction in the risk of death in PwMS relative to the general population when comparing 1968-1980 to 2001-2012. This improvement in survival was not due to overall increases in longevity in the total population – thus the reduction in MS mortality was above and beyond expectation. The **second study** by Koch-Henriksen et al, and published in *Journal of Neurology, Neurosurgery & Psychiatry* used the Danish MS nationwide registry from 1950 to 1999, and linked to several other national health registries. 12,847 PwMS were identified and mortality was compared to known Danish mortality rates for the general population. The highlights of this paper were the results demonstrating between 1950-1959 to

1990-1999 there was a 5-fold reduction in lives lost to MS and survival for PwMS increased 15 years. The *third study* by Lunde et al, and published in *Journal of Neurology, Neurosurgery & Psychiatry* studied all PwMS in Hordaland County, Norway from 1953-2012. 1,388 PwMS were identified through thorough medical record evaluation and linkage to national Norwegian registries. The risk of death for PwMS compared to the general population reduced 3 fold from 1953-1974 to 1997-2012.

Collectively, these studies with exceptionally long study periods and complete sampling of their *source* population (thus, making generalizations easier to their *target* population) demonstrate significant improvements to survival in PwMS. We can only speculate as to the factors responsible for the reduction in mortality, as they were not the primary focus of these studies. Possible factors include: improvements in diagnosis – thus, PwMS are diagnosed earlier and therefore treated earlier; improvements in treatments for MS; improvements in treatments for other chronic and comorbid conditions (i.e. hypertension); changes in access to care; and changes in secular and societal trends (i.e. smoking habits). Considering disease modifying therapies have only been available for two decades, and the dramatic improvements to clinical care in the last several years (reduction in diagnostic delays, improvements to symptom management, etc), I am optimistic life expectancy in PwMS, today or in the very near future, will be closely approaching (if not similar to) that of the general population!

1. <https://www.ncbi.nlm.nih.gov/pubmed/28687718>
2. <https://www.ncbi.nlm.nih.gov/pubmed/28705951>
3. <https://www.ncbi.nlm.nih.gov/pubmed/28365589>

## **Partner Spotlight -- MS Focus**

There are significant implications for those affected by Multiple Sclerosis. If you are a person living with MS and your needs are not provided for by your health insurance or community agencies, you might want to investigate the services that [MS Focus](#) provides. MS Focus is a publicly



funded 501(c)(3) organization whose mission is to improve the lives of people with MS. Whether you are an MS patient, family member or caregiver, one of the MS Focus programs may be able to help.

MS Focus offers a broad range of programs and services. To name a few, MS Focus sponsors a wide variety of classes intended to improve physical and emotional health. Their Cooling Program offers a many items that help MS patients stay cool in the heat. MS Focus also recognizes the importance of being connected online. Their Assistive Technology program provides computers to individuals with MS that may not be able to afford one. Their Brighter Tomorrow Grant assists MS patients more broadly by providing goods or services intended to increase quality of life, ranging from household essentials to hobby supplies. If you are struggling with the healthcare costs, or the cost of living (i.e. rent or utilities), you may be able to turn to one of the MS Focus programs for assistance.

MS Focus programs are offered free of charge in the United States. Their online resources are available throughout the world. You don't need to be a member or participate in fundraising activities to request services. Whether you are a person living with MS who would like to learn more about these services, or you are interested in making a donation to support them, you can learn more by visiting the [MS Focus website](#). We, at the Accelerated Cure Project, appreciate MS Focus' devotion to helping families have the best quality of life possible until a cure is found.

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