

What's in a Brain?

From our partners at the Brain Donor Project and in partnership with the National Institutes of Health

Many patients are interested in helping future generations know more about treating and/or preventing Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). If you are among them, here's something you may want to consider: making arrangements **now** to donate your brain when you die.



There is an urgent need for brain donation for a variety of neurological disorders, including ME/CFS. Breakthroughs in neuroscience require this precious resource, for which there simply is no substitute. And, there are many imaging studies that indicate that the brains of ME/CFS patients have unique characteristics which warrant further study and understanding.

The Brain Donor Project (www.braindonorproject.org) is an innovative not-for-profit that was developed to make high quality, well-characterized brain tissue available for neurological researchers. Their focus is on raising awareness of the critical need for this precious tissue and on simplifying the process for brain donation upon death. The Solve ME/CFS Initiative is so proud to partner with The Brain Donor Project in this effort. Since the NIH has identified a need for the brains of patients who've suffered with ME/CFS to further their research goals, we're anxious to help potential donors understand what's at stake and potentially recruit additional donations for ME/CFS research.

More has been learned about the human brain in the last 20 years than in all of recorded history, but there is so much yet to discover, especially when it comes to a highly perplexing disorder like ME/CFS. You may not be aware that

- Signing up to be an organ donor does **not** mean your brain is included. Separate arrangements need to be made for brain donation.

- Donating your body for anatomical study does **not** mean your brain will be used for neurological research. Again, separate arrangements are needed.
- People who have not been diagnosed with ME/CFS can help, too. Control brains are just as valuable. Brain donation is not disfiguring—an open casket is still an option.
- There's no additional cost to the family for brain donation.
- Arrangements must be made in advance of the time of death.

This is certainly a sensitive decision, and yet our organization has been asked about it many times. If you are interested in learning more about brain donation, starting the process is easy. Just go to braindonorproject.org to get answers to your questions about brain donation. If you're ready to sign up, click on the "Sign Up" button at the top right, and complete the online form. You'll be asked for contact information and whether you've been diagnosed with a neurologic condition. If you are acting on behalf of a loved one with ME/CFS, it's important to know that this must be done prior to the patient passing away.

Please indicate your diagnosis of ME/CFS when you sign up. Your medical records will later be used to verify

Once you submit the form, you'll hear from one of the brain banks within the NeuroBioBank of the National Institutes of Health (NIH) within ten business days. Consent and release forms will be delivered to you, along with instructions for your family. When that time comes, your body will be transported to a medical or mortuary location (at no cost to your family) for the brain to be retrieved and shipped. Time is of the essence at this point, so making arrangements to register in advance helps ensure that all of these arrangements can be accomplished as quickly as possible and the body is then released for whatever funeral arrangements will take place.

If you are interested in making this precious gift, visit braindonorproject.org and start the process. Thank you for considering this invaluable gift as a way to advance science and understanding of ME/CFS. ■