

## Update on the Blazeman Foundation for ALS Tissue Collection

The University of Maryland Brain and Tissue Bank facilitates the donation of ALS tissue that is critical for researchers who need a source of human tissue to determine the initiation events and progression of this terrible disease. With a greater understanding of ALS, scientists can discover the means to prevent and cure ALS. To meet the needs of ALS investigators, the Bank registers patient donors, recruits pathologists for tissue recovery, and recovers and stores tissue for later distribution.

**Registration of Patient Donors:** The patient or family must first make the decision to donate tissue. This is a very personal decision and no one should be pressured to donate. Families can register on the Bank's web site (<http://medschool.umaryland.edu/btbank/family/blazeman.asp>). The decision should be reached as soon as possible since it takes time to make arrangement for the tissue recovery. If the Bank is contacted after someone passes away, tissue recovery may not always be feasible although the Bank will make every effort to fulfill the wish to donate.

**Identify and Recruit Pathologists for Tissue Recovery:** Since recovery of tissue could potentially occur in any part of the US, the Bank relies on pathologists that are local to the donor. The Bank has the trained staff that makes these arrangements. The University of Maryland Brain and Tissue Bank has institutional approval to recover tissue anywhere in the US once consent is received from the donor family.

**Tissue Recovery:** The Bank collects the spinal cord, spinal fluid and brain as well as muscle and peripheral nerve tissues. Recovery of these tissues is expensive. The primary expense to the Bank is for the pathologist; however, the Bank also incurs costs for shipping and for completion of a neuropathology report. The tissue is also evaluated for quality to assure researchers that it will be appropriate for their research.

### The Blazeman Foundation for ALS' Contribution to Tissue Recovery:

The generosity of donors to the Blazeman Foundation for ALS has helped make it possible for the Bank to recover tissue from 22 ALS donors of which to date 16 researchers worldwide have received this important tissue. Added to that, the foundation educates the ALS community on the need of ALS tissue donation through their brochure which has been distributed to ALS centers and organizations throughout the US. Before our support from the Blazeman Foundation for ALS we had only collected a small amount of ALS tissue. New researchers often contact the Bank to request tissue...many of these researchers do not belong to consortiums that distribute such tissue. More tissue is needed so that researchers have the tissue required to propose and perform novel studies that will lead to elimination in the near future of this scourge to humanity. The University of Maryland Brain and Tissue Bank appreciates the financial support that the Blazeman Foundation for ALS is making towards this effort.

UNIVERSITY OF MARYLAND BRAIN AND TISSUE BANK - An Affiliate of the NIH NeuroBioBank: <https://neurobiobank.nih.gov>

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