Target ALS Multicenter Postmortem Tissue Core

Request for Samples

**Name/ Position:**

**Institution:**

**Shipping Address**:

**Telephone:**       **Fax**:       **Email:**

**Shipping Account Number (e.g. Fedex):**

**Research Project Title:**

**What type of samples are you requesting?**

[ ]  Paraffin Sections [ ]  Fresh frozen tissue

**If requesting multiple regions, do they need to be from the same cases?**

[ ]  Yes [ ]  No [ ]  Preferred, but not absolutely necessary.

*Frozen tissue is generally provided as ~75-200 mg individual samples (varies depending on anatomical region) and paraffin-embedded tissues as unstained “Plus-coated” glass slides. Larger samples of certain regions may be available if justified by experimental methods. When performing quantitative assays on frozen spinal cord tissue, we recommend using cryostat sections for lysis/homogenate preparation, ensuring a homogenous and unbiased selection of ventral/dorsal and white/gray matter.*

*\*Slide and frozen tissue numbers and sample volumes must be justified in experimental plan section (on next page).*

**For fixed, paraffin-embedded tissue, please specify the number of slides requested per region:**

**For frozen tissue, please specify the minimum volume needed per sample (in mg):**

**If both paraffin and frozen samples are requested, do they need to be from corresponding cases and regions?**

[ ]  Yes [ ]  No [ ]  Preferred, but not absolutely necessary.

**Please specify the number of cases requested:**

      Non-Neurologic Controls – *we will do our best to match demographics to ALS cases*.

 ALS Subjects (sALS or fALS)

 Sporadic ALS

Familial ALS (regardless of mutation or mutation unknown, or specify below)

 SOD1 C9orf72 Other (describe below)

**We will do our best to provide tissue from patients with specific clinical characteristics if requested.** *Data collected on every case includes race, gender, age at symptom onset, anatomic site of symptom onset (bulbar, R/L/bilat LE/UE, combinations), disease duration (in months), age at death, post-mortem interval, family history of ALS or FTD, UMN vs LMN pattern (5 pt scale – UMN only, UMN>LMN, UMN=LMN, UMN<LMN, LMN only), known genetic results (C9orf72, SOD1, etc), and other medical diagnoses. Please detail specific patient characteristics requested below:*

**What regions are you requesting?**

**Cortical regions**

[ ]  primary motor

[ ]  primary sensory

[ ]  frontal pole

[ ]  temporal

[ ]  occipital

[ ]  **Cerebellum**

[ ]  **Muscle**

[ ]  **Liver**

**Brainstem**

 [ ]  midbrain [ ]  pons [ ]  medulla

**Spinal cord**

 [ ]  cervical [ ]  thoracic [ ]  lumbosacral

 [ ]  cervical OR lumbar [ ]  Any spinal cord region

[ ]  If “cervical OR lumbar” or “Any” are checked above, need all samples/slides to be from the SAME region.

[ ]  **Other** (*Describe below).* Many other cortical and deep CNS regions are available, as well as DRGs, choroid plexus, sensory and motor nerve roots, peripheral nerve, and other organs.

**Assistance with Assay Development**

If you have not validated your assay/staining technique using human CNS tissues, we will provide test tissues before providing more high-demand samples. These tissues are often from cases for which data is incomplete - for example tissue from unclear cortical regions, for which full donor demographics are not available, or clinical histories are incomplete. Alternatively, in some cases we may be able to provide less scarce or less high-demand samples, such as cerebellum, temporal cortex, parietal cortex, thoracic cord, etc. (ie never motor cortex or cervical/lumbosacral spinal cord).

If you are requesting these tissues, please detail below:

*Note that test sample sets will generally be blinded (and will include duplicates), but we can also provide unblended samples to help with assay development when appropriate.*

**Experimental Plan**

*Please limit to two pages (****shorter is better****). The experimental plan should include a brief rationale, preliminary data, and specifically demonstrate that you have performed the assay/staining protocols successfully on human CNS tissues.*

***Importantly, you must provide justification for the number of cases, need for specific genetic cases, sample sizes, and number of slides requested.***

*Please also provide a very brief outline of the experimental plan, and method of data interpretation. We generally are not reviewing scientific merit, but rather experiment feasibility and the justification of sample quantities to ensure that the samples are used responsibly.*

**Funding Information**

Do you currently have funding for this project? [ ]  Yes [ ]  No

Will the tissue samples and/or patient data be used in connection with research supported by industry? [ ]  Yes [ ]  No

**Process and Timeline for Obtaining Samples for Research**

* Applications are reviewed on a rolling basis within two weeks of receipt, using established criteria that emphasize experimental feasibility and appropriateness of sample sizes and quantities.
* After initial review, a direct phone call is scheduled with the Core co-Directors to address any questions or concerns, after which the best samples to suit your needs will be identified across our core sites.
* If your assays/staining procedures have not been validated on human CNS tissues, we will arrange to send a blinded test sample set first to help with assay development.
* Once the samples have been identified, MTAs with standardized language will be provided for each Core Site that will be sending tissue. Separate MTA language for Academic/non-Profit and Industry/for-Profit requests has been standardized and pre-approved by each Core Site. The local Site Coordinators will prepare the tissues for shipment so that they can be shipped as soon as the MTA’s are executed.
* **Researchers pay for shipping of samples. There is an additional transmittal fee requested for Industry/For-Profit requests of $50 per slide and $200 per frozen tissue sample**.
* We recommend that tissues are sent blinded to the demographic data, though this is not an absolute requirement. We are happy to un-blind the data at any time.

**Once you have received samples, we require the following:**

1. ***You must provide a summary statement to Target ALS within 6 months of receiving the samples, detailing how they were used and listing any publications, meeting abstracts, or grant proposals that used the samples. Email to*** **ms4739@georgetown.edu*****.***
2. ***Please email any subsequent publications, meeting abstracts, or grant proposals to the*** **Target ALS** ***when available.***
3. *“****The Target ALS Multicenter Postmortem Tissue Core****” must be acknowledged in any publications and meeting abstracts/presentations.*
4. *Co-authorship inclusion on publications is not required but is encouraged if any Target ALS Site PI’s directly assist in assay development, analysis, or other aspects of a given project.*
5. *Our database/tissue inventory will link the following information to the samples used to help foster collaboration and prevent duplication:*
	* *Links to any publications using the samples.*
	* *The types of experiments performed (ie not the experimental results, but rather egs western blot for xxx, immunostaining for xxx, etc).*
	* *Contact information for the researchers that performed the experiments*

**Genetic Data**

Whole Genome Sequencing and multiple region RNA-Seq are performed on all autopsy cases at the New York Genome Center (NYGC). This constantly growing data set is made freely available to both academic and industry researchers. **For this reason, we generally do not provide tissues specifically for RNA-Seq or WGS unless the data sets generated by the NYGC does not fulfill your needs**.

WGS and RNA-Seq raw data files can be requested via our [**Genetic Data Request Form**](https://metronome.nygenome.org/TargetALS/TargetALSGeneticDataRequestV7.doc). Detailed information about sample processing, QC, and analysis are available for the [**WGS**](https://metronome.nygenome.org/NYGC-WGS-QC-README_29Jun2017.pdf) and [**RNA-Seq**](https://metronome.nygenome.org/NYGC-RNA-Seq-QC-README_29Jun2017.pdf) data.

**If you have any questions about the information requested in this application, the samples available for research, or any other matters related to the Tissue Core, please do not hesitate to contact the Core co-Directors, Drs. Robert Bowser (****Robert.Bowser@DignityHealth.org****) and Brent Harris (****bth@georgetown.edu****).**

We are happy to discuss your project at any time and do whatever is necessary to expedite this process, ensure that you receive the best possible samples for your research, and that your experiments are successful.

**Please email this completed form and an NIH-style biosketch to:** **ms4739@georgetown.edu****.**

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