

# ALS Animal Model Resources

## Mice

**ALZForum ALS Mouse Model Database** – Organized phenotypic information to facilitate comparisons between over 40 ALS mouse models.

**European Mutant Mouse Archive** – More than 8,700 mutant mouse strains and a limited number of rat mutant strains are available. Includes several ALS-relevant strains with mutations in FUS, Tardbp, OPTN, PFn1, SOD1, Setx, Sqstm1, Vapb, C9orf72 and others.

**Jackson Labs ALS Mouse Model Resource** – The Jackson Laboratory's website to identify and select ALS mouse models and to find multiple helpful resources.

**Mutant Mouse Resource & Research Center** – NIH-funded mouse lines and embryonic stem (cells, as well as related products and services.

## Other Animals

**Bloomington Drosophila Stock Center ALS Fly Models** – Collects, maintains, and distributes *Drosophila melanogaster* strains for research. Includes strains with mutations in SOD1, Alsin, SETX, FUS, VAPB, ANG, TARDP, FIG4, OPTN, ATXN2, UBQLN2, PFn1, TAF15, and EWSR1. Also has multiple [C9orf72-relevant mutant strains](#) with different GGGCC expansions.

**The Zebrafish Information Network** – A database resource for the laboratory use of zebrafish genetic models. Part of the Alliance of Genome Resources. Information on multiple [ALS Zebrafish models](#), including SOD1, FUS, and TARDBP mutants.

**Alliance of Genome Resources** – A consortium of seven model organism databases and the Gene Ontology Consortium. The Alliance includes FlyBase, The Mouse Genome Database, The Gene Ontology Consortium, The Saccharomyces Genome Database, The Rat Genome Database, WormBase, Xenbase, and The Zebrafish Information Network.

# Biorepositories – Biofluids and Cell Lines

**Answer ALS iPS Cells & Motor Neurons** – The Answer ALS Research Project entails creating up to 1,000 unique stem cell lines from ALS patient participants and healthy controls. For information on ordering the iPSCs Lines from Cedars Sinai, [click here](#). Linked clinical, genetic, molecular, and biochemical data can be explored in the [Answer ALS Neuromine Portal](#), and used to select and order the corresponding cell lines.

**CDC National ALS Registry Biorepository** – Multiple types of [biosamples](#) collected from persons with ALS who are enrolled in the National ALS Registry, including pre-mortem DNA, RNA, fibroblasts, PBMCs, plasma, serum, whole blood, and RBCs, and post-mortem primary cells and CSF. For information on requesting data and/or samples, [click here](#).

**Cedars Sinai Induced Pluripotent Stem Cell Core** – The Core is involved in many ALS projects, including Answer ALS, NeuroLINCS, Track ALS, and the SMA Collection. They have a [searchable online database](#) of ALS cell lines, including ALS, PLS, non-ALS MND, and SMA lines.

**NEALS Sample Repository** – Biofluid samples collected from numerous ALS clinical trials and biofluid collection efforts of the [Northeast ALS Consortium](#). To apply for samples, visit the NEALS [Sample Request Portal](#).

**NeuroLINCS** – NIH funded collaborative effort between research groups with expertise in iPSC technology, disease modeling, OMICS, and computational biology. The [data page](#) has links to multiple ALS and SMA iPSC-derived data sets as either raw accessed via dbGaP or Chorus, or accessed via LINCS Data Portal transcriptomic, proteomic, epigenomic data collected by participating sites.

**Target ALS Stem Cell Core** – Lines are stored and disbursed by the [NINDS Human Cell and Data Repository](#). For instructions on accessing the Target ALS Lines: [click here](#).

**UK MND Collections** – Sample collections and data curated by the [Motor Neuron Disease Association](#), including:

- The [DNA Bank](#): >3,000 blood samples, stored at CIGMR (Centre for Integrated Genomic Medical Research) in Manchester, UK; also has clinical information (divided into a minimum and extended dataset) available to researchers.
- The [Cell Lines Collection](#): A sub set of the DNA Bank samples as lymphoblastoid cell lines and peripheral blood lymphocytes; enable the creation of induced Pluripotent Stem Cells.
- The [Epidemiology Collection](#): >200 patient and matched control surveys including extensive environmental and lifestyle data from self-report questionnaires and telephone interviews as well as a subset of genomic DNA samples.

# Biorepositories – Postmortem Tissues

**CDC National ALS Biorepository** – Postmortem tissues include brain, spinal cord, bone, and muscle from 52 ALS patients who were enrolled in the [CDC National ALS Registry](#). To request samples and data, visit the national ALS Biorepository [Researcher Information page](#).

**Department of Veteran Affairs Biorepository Brain Bank** – Neurological tissue specimens from Veterans who died from ALS, and more recently has added enrollment of non-ALS Registry veterans. Phenotype data includes semi-annual ALSFRS-R/EX, with additional postmortem proxy interview, cognitive assessments, detailed health information from surveys and VA electronic medical records. Investigators are highly encouraged to discuss their requests with the VABBB before applying, by contacting Ian Robey, Ph.D. at 520-792-1450 x4436 or [Ian.Robey@va.gov](mailto:Ian.Robey@va.gov). Click these hyperlinks for: a brochure for investigators, A brochure is available for investigators.

**Netherlands Brain Bank** – The NBB contains >4,000 autopsies with a variety of neurological and psychiatric disorders, and non-demented controls. Also banks CSF, plasma, and sometimes spinal cord and dorsal root ganglia. There is [online access](#) to search the NBB database (requires registering for an account), and [detailed information on the sample request and review process](#), including downloadable application forms.

**NIH NeuroBioBank** – Postmortem Brain Tissues collected by six biorepositories, University of Miami, University of Maryland, Harvard, the Human Brain and Spinal Fluid Resource Center, Mt. Sinai Brain Bank, University of Pittsburgh. Not specific for ALS but contains ALS autopsies. Has an online [inventory search website](#) and [instructions for requesting tissues](#).

**Target ALS Postmortem Tissue Core** – Autopsies are performed at five academic ALS centers, Barrow Neurological Institute, Columbia University, Georgetown University, University of California San Diego, and Washington University St. Louis, according to harmonized SOPs for tissue dissection and clinical data collection. Whole Genome Sequencing and bulk tissue RNA-Seq for multiple central nervous system regions are available from the [NYGC ALS Consortium](#). For any questions or to inquire about new or existing tissue requests, please email Marina Selenica at [ms4739@georgetown.edu](mailto:ms4739@georgetown.edu).

**Temple University ALS Postmortem Core** collaboration with the [CDC National ALS Registry](#) Includes frozen and fixed CNS tissues, liver, and muscle samples from 100+ ALS/MND and non-neurological control autopsies, linked to de-identified clinical, demographic, neuropathological, genomic, and QC data. Whole Genome Sequencing and bulk tissue RNA-Seq for multiple central nervous system regions are also available from the [NYGC ALS Consortium](#) – linked to the tissue samples and slides. Contact the Core Director, Dr. Lyle Ostrow M.D., Ph.D., ([Lyle.Ostrow@tuhs.temple.edu](mailto:Lyle.Ostrow@tuhs.temple.edu)) or the Core Manager, Kathleen Wilsbach, Ph.D., [Kathleen.Wilsbach@temple.edu](mailto:Kathleen.Wilsbach@temple.edu), for more information and a sample request form.

**Temple University Postmortem Lytico-Bodig Resources** – includes fixed and frozen postmortem tissues, serum, including controls and longitudinal samples, CSF, and detailed records from over 400 decedents who died from ALS, Parkinson's-Dementia Complex, and controls. The samples and data were collected on the island of Guam over many decades and recently incorporated into the Temple ALS Postmortem Core thanks to support from the CDC National ALS Registry. Contact Dr. Lyle Ostrow M.D., Ph.D., ([Lyle.Ostrow@tuhs.temple.edu](mailto:Lyle.Ostrow@tuhs.temple.edu)) for a request form and further information about the samples and data.

**UK Brain Banks Network** – Supplies tissue samples to academic and industry researchers in the UK and internationally from [multiple participating brain banks](#). Not ALS specific but includes motor neuron disease autopsies at many centers.

# ALS Data Sets, Data Analysis Tools, and Data Visualization Platforms

**[ALS Online Database \(ALSoD\)](#)** – collates information about genes and genetic variants connected to ALS. Includes links to publications and summary information on each gene, strength of evidence, lists of variants, and phenotype visualizations incorporating age of onset, sex, site of onset, family history, and variant type.

**[ALS TDI ARC Data Commons](#)** – gives researchers access to over 8 years of de-identified natural history data contributed by people living with ALS. There is an online request form [here](#).

**[Answer ALS NEUROMINE Data Portal](#)** – Incorporates de-identified clinical information on 1,200+ participants, linked to comprehensive genomic, epigenomic, proteomic, and transcriptomic data. The data can be explored with multiple analysis and visualization tools, downloaded, and used to identify and order the corresponding [Answer ALS Cell Lines](#).

**[CDC National Amyotrophic Lateral Sclerosis Registry](#)** – Congressionally mandated program to collect, manage, and analyze data about persons with ALS. Extensive demographic and risk factor data is available, including residential and occupational histories, toxic and environmental exposures, family history, trauma, military history, and more. There is a [website with instructions on requesting data](#), and a [Research Application Form](#).

**[ClinGen ALS Gene-Disease Validity Classification Reports](#)** – [ClinGen](#) is an NIH-funded resource dedicated to defining the clinical relevance of genes and variants for use in precision medicine and research. The ALS Gene Curation Expert Panel, chaired by ALSRP Programmatic Panel member Dr. Matthew Harms, MD, evaluates the evidence for genes that have been linked to the phenotype of ALS, and generates detailed [classification reports](#) for each gene.

**[Database of Genotypes and Phenotypes \(dbGaP\)](#)** – Archives and distributes data and results from studies examining the interaction of genotype and phenotype in humans.

**[Everything ALS Austen Speech Study](#)** – 1200 hours of speech data collected over 7,000 sessions from 850 participants. The website has an online form to request access to the open data. Email [speech@everythingals.org](mailto:speech@everythingals.org) or [info@everythingals.org](mailto:info@everythingals.org) for more information.

**[Hammell Lab Bioinformatics Software](#)** for high throughput sequencing analysis, particularly useful in analysis of transposable elements and other repetitive sequences. Have been used to analyze the NYGC ALS Consortium data (see [manuscript](#)) and for several other ALS-retrotransposon projects.

**[NEALS Historical Trial Data](#)** – De-identified data from multiple ALS trial databases, available for researchers to mine. To request access to the NEALS data sets, fill out a [Data Request Form](#) and submit the completed form to Carly Allen at [callen@neals.org](mailto:callen@neals.org).

**[NIH NeuroBioBank](#)** – Genome-wide genotyping and whole genome sequence (WGS) data from >9,500 subjects from the NIH NeuroBioBank – not specific for ALS but includes ALS. The publicly available web page for this study in the NIMH Data Archive is [here](#). To access, search and analyze this dataset, apply for access [here](#). Once approved, you will be able to access the data in collection #3917. There are helpful tutorials about accessing data [here](#). Contact [NDAHelp@mail.nih.gov](mailto:NDAHelp@mail.nih.gov) with any additional questions.

**[NYGC ALS Consortium](#)** – A partnership of clinicians, basic scientists, geneticists, and computational biologists from 45 institutions around the globe to apply whole genome sequencing and functional genomics to the study of ALS. The current dataset contains WGS data from >4,300 whole genomes and 2,300 RNA samples, linked to harmonized clinical phenotype data.

**Pooled Resource Open-Access ALS Clinical Trials (PRO-ACT) Database** – Over 11,600 fully de-identified clinical patient records from the placebo and treatment-arm data of 29 Phase II/III Clinical Trials. Includes demographic, lab, medical, and family history, and other data elements. More than 10 million longitudinally collected data points.

**Project MinE** – Project to perform whole-genome sequencing (WGS) of 15,000 ALS patients and 7,500 controls. The current dataset >11,000 DNA profiles, of which >6,400 profiles are available via an online [open-access Data Browser](#). Information on requesting the data is available [here](#), including an [online form to request the WGS data](#).

**NYGC ALS Spatial Transcriptomics Portal** – An interactive data exploration portal for the spatial transcriptome atlas of the ALS spinal cord. Includes multiple time points in G93A and wildtype mice, and postmortem human spinal cord. Downloadable [user guide](#) and companion [manuscript](#).

# Antibodies and other Reagents

## [Abcam ALS antibodies and disease-related markers](#)

[ALS Reproducible Antibody Platform \(ALS RAP\)](#) – created as a public-private partnership by the ALS Association, the Motor Neurone Disease Association (UK), and the ALS Society of Canada to ensure the availability of the highest quality, validated antibodies developed using standard operating procedures that will be openly shared with the ALS research community. Notably, no form of intellectual property protection or patents will be filed for all new reproducible antibodies fully discovered and developed by ALS-RAP. This collaborative effort, based on open science and complete freedom to operate, will ensure the use of the highest-quality tools to increase the success of future drug discovery.

## [Proteintech Antibodies for ALS and FTD](#)

[Target ALS Antibody Core](#) – Currently available antibodies include C9orf72 Poly(GP) Monoclonal antibody, Mouse Vacht Polyclonal Antibody, and a Rabbit polyclonal TDP-43 antibody.

# Clinical Research Tools and Resources

[ALS TDI / Google AI Machine Learning Based Objective Measure for ALS Disease Severity](#) – Incorporates voice recordings, accelerometer data, and self-reported ALSFRS-r scores from people living with ALS enrolled in ALS TDI's [Precision Medicine Program](#). The code for the machine learning algorithm is available on [Github](#), and the companion manuscript published in Nature Digital Medicine is available [here](#).

## [Emory ALS Center Outcome Measures and Resources:](#)

- **Rasch-built Overall ALS Disability Scale ROADS** – Funded by an ALSRP Clinical Development Award AL200156 to Dr. Christina Fournier at Emory University School of Medicine, the ROADS is a self-reported ALS disability scale. A [JAMA Neurology manuscript](#) details the development and validation of the ROADS. The [ROADS Form](#) is available for download, and a training manual is [here](#).
- **The Motor Observational Telemedicine Objective Rasch-Built Assessment, ALS MOTOR** – The ALS MOTOR is an objective, standardized, telemedicine-based exam scale to assess overall motor strength in people living with ALS. The [ALS MOTOR FORM](#) is available for download, and a training manual is [here](#).

[ENCALS Outcome Measures](#) – Information and training modules on the standardized core protocols, data sets, and outcome measures used by the European trial network TRICALS.

## Platforms to Search for Clinical Trials

[ALS Signal](#) – A searchable platform of information on ALS clinical trials around the world, created and maintained by [I AM ALS](#).

[ALS Trial Navigator](#) – A guided user-friendly tool created by [ALS TDI](#), which generates a curated list of ALS clinical trials based on specified preferences and eligibility criteria.

### [Antidote Match](#)

[Clinicaltrials.gov](#) – database of privately and publicly funded clinical studies conducted around the world.

### [Northeast ALS Consortium Clinical Trial Database](#)

[National ALS Registry Trial Recruitment Notification System](#) – enables persons with ALS enrolled in the Registry to receive automatic notifications about clinical trials for which they may be eligible. Researchers who would like their studies included in the notification system can email [alsresearch@cdc.gov](mailto:alsresearch@cdc.gov). More information [here](#).