ALS BIG DATA RESOURCES

RESOURCE	DESCRIPTION
ALS-CarE	The purpose of ALS-CarE is to use existing information drawn from partner countries into a system of care that is available to people with ALS at the correct time, in the correct format and in a cost-effective manner. This will be achieved by collecting details of patient and carer experiences across all stages of from diagnosis to end of life, including decision making in the terminal stages of the disease. A health economic analysis will help to identify the overall costs of disease management, provide models of increased efficiency that preserve and maximize quality of life, and begin to develop novel health economic measurement tools for terminal neurological illness.
ALSoD	The ALS Online Database is a freely available database that has developed a single gene storage facility recording mutations in the SOD1 gene to a multigene ALS bioinformatics repository and analytical instrument combining genotype, phenotype, and geographical information with associated analysis tools.
ALSTDI	The ALS Therapy Development Institute and its scientists actively discover and develop treatments for ALS. It is the world's first and largest non-profit biotech focused 100 percent on ALS research. Led by people with ALS and drug development experts, they understand the urgent need to slow and stop this disease.
ALS Reproducible Antibody Platform	ALS-RAP was formed 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.
AMBRoSIA **A M**ulticentre **B**iomarker **R**es**O**urce **S**trategy **I**n **A**LS	An ongoing 5-year longitudinal study that has grown out of BioMOx and the UK ALS Biomarkers study. It aims to recruit several hundred participants across three UK hospitals, collecting blood, CSF fibroblasts and clinical data.
ANSWER ALS	Comprehensive clinical, genetic, molecular & biochemical assessment of ALS, while openly sharing the results with the global research community.

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BioMOx **Pre-FALS** **UK ALS Biomarker**	A 10-year initiative to study ~80 MND patients (of all disease sub-types, including PLS) every six month, with multi-modal imaging and bio sample collection. Studies of healthy volunteers and those with other conditions affecting motor nerves on a single occasion were used as a comparison. BioMOx collaborates closely with the US-based Pre-FALS study and with the UK ALS Biomarker study
BRAIN-MEND	BRAIN-MEND will use the latest methods in genetics and epigenetics to find causes of neurodegenerative diseases (not just ALS) combining these results to identify new drug targets. At the same time, we will use machine learning to analyse medical literature and patient records to find clusters of symptoms which might suggest new disease groups. A key outcome of BRAIN-MEND is to disentangle the different neurodegenerative diseases, so that for any patient group we can understand how, in some cases, different causes may produce the same clinical picture, while in other cases the same cause may produce different clinical pictures.
Cedars-Sinai iPSC Core	The Brain Program at the Cedars-Sinai Regenerative Medicine Institute comprises a group of scientists studying a variety of neurological diseases of the peripheral and central nervous system using stem cell technology as their primary research tool. Several groups have a particular focus on using induced pluripotent stem cells (iPSCs) to research neurological diseases.
CReATe	The ***C****linical* ***Re****search in* ***A****LS and Related Disorders for* ***T****h****e****rapeutic Development (****CReATe****)* Consortium will enroll patients with sporadic and familial forms of amyotrophic lateral sclerosis, frontotemporal dementia (**FTD**), primary lateral sclerosis (**PLS**), hereditary spastic paraplegia (**HSP**), and progressive muscular atrophy (**PMA**). The goals of the CReATe consortium are to advance therapeutic development for this group of neurodegenerative disorders through study of the relationship between clinical phenotype and underlying genotype, and also through the discovery and development of biomarkers.
Database of Genotypes and Phenotypes	Archives and distributes data and results from a wide range of studies examining the interaction of genotype and phenotype in humans.

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Department of Veteran Affairs Biorepository Brain Bank	Collects, processes, stores, and gives out neurological tissue specimens from Veterans who died from ALS or related motor neuron disorders (PLS, PMA, PBP). Veterans without ALS or other neurological diseases (Non-Neurological Controls) are also collected.
EuroMOTOR	Multi-omics initiative to discover new causative and disease-modifying pathways to pave the way for novel therapies in Amyotrophic Lateral Sclerosis (ALS). To achieve this goal large-scale quantitative data sets were generated in order to integrate and deliver an ALS computation model.
Institute for Genomic Medicine	The Institute for Genomic Medicine is establishing a cohesive, Columbia-wide research and teaching environment for human genetics and genomics. Working with the University and our partners, the IGM is driving innovation in genomic medicine through vibrant research, clinical applications and outreach efforts. Our genetics environment offers the benefits of scale and expertise that facilitates the integration of genomic analysis across the Columbia community.
National ALS Registry	The National ALS Registry is a congressionally mandated registry for persons in the U.S. with ALS. It is the only population-based registry in the U.S. that collects information to help scientists learn more about who gets ALS and its causes.
National Amyotrophic Lateral Sclerosis (ALS) Registry	Inventory of samples currently available from the National ALS Biorepository.
NEALS	NEALS Sample Repository NEALS and the Massachusetts General Hospital Neurological Clinical Research Institute (NCRI) and Barrow Neurologic Institute (BNI) have a repository of serum, plasma, cerebrospinal fluid (CSF), whole blood, extracted DNA, and urine samples from NEALS and NCRI research studies of amyotrophic lateral sclerosis (ALS) and motor neuron disease. The repository is partially funded by The ALS Association and samples from this repository are available to researchers for the purpose of furthering the understanding of ALS or motor neuron disease and developing disease biomarkers.

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NEALS Historical Trial Data	De-identified data from multiple ALS trial databases, available for researchers to mine.
NETCALS	The aim of this community-led Working Group is to establish 'best practice' guidelines and a methodological framework for data sharing/handling, outcome measures (including training and certification) standards for neuroimaging/neurophysiology and clinical data linkage in population-based cohorts of ALS patients.
NeuroBANK®	NeuroBANK™ is the flagship platform for collecting data on research volunteers who participate in natural history studies or in multiple projects within a disease consortium.
Netherlands Brain Bank	Part of the BrainNet Europe II, the NBB contains >4,000 autopsies with a variety of neurological and psychiatric disorders, and non-demented controls. Also provides CSF, plasma, and sometimes spinal cord and dorsal root ganglia.
Neuro-LINCS	NeuroLINCS is an NIH-funded collaborative effort between research groups with expertise in iPSC technology, disease modeling, OMICS methods, and computational biology. NeuroLINCS seeks to understand the causes of neurological diseases and to develop new therapies.
New York Genome Center	Making harmonized and de-identified genetic data freely and broadly available to the entire ALS research community.
NYGC ALS Spatial Transcriptomics Portal	Whole genome sequencing (WGS) and multiple CNS region RNA-Seq are performed at NYGC on all of the Target ALS Postmortem Cases. These constantly growing raw genetic and transcriptomic data sets are made immediately and freely available to both academic and industry researchers without IP or authorship concerns, and are linked bank to the tissue samples and de-identified metadata so that samples or slides with specific genetic/transcriptomic features can be requested for benchtop experiments. rpPCR testing for C9orf72 and Ataxn2 repeat expansions are separately performed on each case, along with Illumina/ExpansionHunter analysis.

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NIH NeuroBioBank	Postmortem Brain Tissues collected at six academic centers (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.
NISALS Neuroimaging Society in ALS	The NiSALS website has been set up to provide an interactive platform for research centers specializing in Amyotrophic Lateral Sclerosis neuroimaging research. The JENA MRI repository provides a centralized storage system where participating centers can upload de-identified MRI datasets of patients and healthy control persons for collaborative research in ALS.
PRO-ACE	The PRO-ACE platform harmonizes, de-identifies, aggregates, and stores clinical research data for secondary analyses. The PRO-ACE dataset contains data collected from ERB/IRB approved observational studies, retrospective clinical assessments, population registries and other clinical datasets.
PRO-ACT	Over 10,700 fully de-identified clinical patient records Placebo and treatment-arm data from 23 Phase II/III clinical trials Demographic, lab, medical and family history, and other data elements More than 10 million longitudinally collected data points
Project MinE	A global initiative (20 countries) that aims to sequence the genomes (GWAS, WGS) and epigenome (EWAS) of 22,500 individuals (15,000 ALS).
SOPHIA **S**ampling and biomarker **OP**timization and **H**armonization **I**n **A**LS and other motor neuron diseases.	The SOPHIA consortium was created to address the need to develop biomarkers for ALS, through development of a platform for researchers to optimize/harmonize novel biomarkers using an established pan-European ALS methodology and agreed standards.
STRENGTH **S**urvival, **T**rigger and **R**isk, **E**pigenetic, e**N**vironmental and **G**enetic **T**argets for motor neuron **H**ealth.	The aim of STRENGTH was to discover factors that change the risk of ALS, trigger ALS or affect how rapidly it progresses, though analyses of genetic data, exposure information and clinical information from people with ALS enrolled in pan-European population registers covering a population of about 120 million people.

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Target ALS Antibody Core	Creating a panel of high quality monoclonal and polyclonal antibodies, made available to the ALS research community worldwide. Currently available: Poly(GP)monoclonal antibodies from two hybridoma clones. Both have been deposited at the Developmental Studies Hybridoma Bank (DHSB). Mouse Vacht polyclonal antibody. Investigators can request up to 10 aliquots (20 ul/aliquot).
Target ALS Human PM tissue inventory	We have defined standard operating procedures for tissue acquisition and dissection, processing, storage, histopathological characterization and QC analysis, all specifically optimized for ALS research. Tissue inventories from our multiple core sites and the corresponding de-identified clinical metadata are linked using platforms developed by the Center for Innovation & Bioinformatics. A web-based searchable database of the postmortem tissue inventory provides estimates of fixed and frozen postmortem tissues available that meet basic demographic criteria.
Target ALS Stem Cell Core	Cell lines are provided with no reach through on data or intellectual property.
TONiC **T**rajectories of **O**utcome **i**n **N**eurological **C**onditions	A UK study combining cross-sectional and longitudinal clinical data, patient reported outcome measures and health economics analysis to examine the physical, psychological and social factors and how they interact to influence quality of life in people with ALS.
TRICALS **Tri**als **C**onsortium to Cure **ALS**	Pan-European initiative which aims to build on the foundations laid through the preceding initiatives (bringing together researchers, funders and patients/patient associations) with clinical trials at the heart of the activity. To be launched November 2019.
UK MND Collections	Formerly the UK MND DNA Bank. A collection of DNA, PBLs/LCLs and clinical data, with additional sub-cohorts (epidemiology data, FALS iPSC lines). Administered by the MND Association. Nearly all ALS DNA samples have undergone GWAS and WGS as part of the Project MinE initiative.
UK Brain Banks Network	MRC directed national network of UK Brain Banks using common protocols to collect and store tissues. The network provides high quality brain tissue to academic and industry researchers in the UK and internationally. Not ALS specific, but includes motor neuron disease autopsies at many centers. Researchers can use an online searchable database (requires registration), which contains details of the samples available.

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UMass ALS Variant Server (AVS)	The goal of the ALS Variant Server is to provide researchers with a database of variants identified from exome sequencing of ALS cases