



Advancing ALS research, one sample at a time...

What is the National ALS Biorepository?

The National ALS Biorepository is a component of the National ALS Registry that

collects ····> processes ····> stores



and distributes a variety of biological samples from a geographically representative sample of persons with ALS enrolled in the National ALS Registry.

The National ALS Registry, maintained and operated by the federal Agency for Toxic Substances and Disease Registry (ATSDR), is a congressionally-mandated registry for persons in the U.S. with ALS. It is the only populationbased registry in the U.S. that collects information to help scientists learn more about who gets ALS and its potential causes.

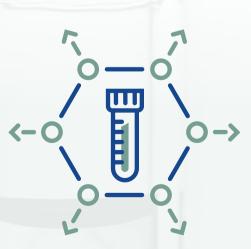
How is the National ALS Biorepository different from other biorepositories?

The National ALS Biorepository collects specimens from a nationally representative sample of people with ALS in the U.S. that is not tied to a specific clinic or location. Researchers can obtain complementary epidemiological data not usually collected by a biorepository, e.g., military history, family history, and occupational history. Samples are accessible to researchers around the globe regardless of institutional affiliation.



How do I request samples?

For information and to obtain samples, visit the National ALS Biorepository website, www.cdc.gov/ als/ALSNationalBiorepository.html, or call toll free at (855) 874-6912. Research proposals are reviewed to ensure that access to National ALS Biorepository resources is restricted to ALS research projects with appropriate oversight and protection of human subjects.





www.cdc.gov/als/ALSNationalBiorepository.html

What types of samples are available?

Blood, serum, plasma, DNA, RNA, PBMCs, urine, hair, and nails were collected from people with ALS. In addition, samples of brains, spinal cords, CSF, bone, muscle, and human primary cells derived from skin are available from a subset of people with ALS in the National ALS Registry.

Are there costs associated with receiving samples?

Unlike some repositories, the cost of collection and storage of samples is not passed on to researchers requesting samples. However, researchers can expect to incur a per sample retrieval cost, along with shipping costs to deliver samples. You can call and ask for an estimate of costs to get samples.

Who can request samples?

Any ALS researcher, regardless of institutional affiliation or location, can request samples. You and your research do not need to be based in the U.S. The process to obtain samples is the same no matter where you are in the world.

About ATSDR

The Agency for Toxic Substances and Disease Registry (ATSDR) is the federal agency charged with identifying environmental health hazards and working with federal, tribal, state, and local agencies to address them. ATSDR uses registries to track information to learn more about possible relationships between toxic substances and diseases.



For More Information: The National ALS Biorepository 4770 Buford Highway NE, MS S102-1 Atlanta, GA 30341 Toll free: (855) 874-6912 www.cdc.gov/als/ALSNationalBiorepository.html



