



The National Amyotrophic Lateral Sclerosis (ALS) Biorepository

The National ALS Biorepository (Biorepository) is part of the National ALS Registry. It will include samples from persons with ALS (PALS) who are enrolled in the National ALS Registry.

LEARN MORE AT WWW.CDC.GOV/ALSBIOREPOSITORY OR CALL (855)-874-6912

Biorepository

The term biorepository usually refers to a facility that collects and stores samples of biological material. These samples could include blood, urine, tissue, cells, DNA, and proteins. Some medical data may also be stored along with a written consent form.

The Importance of this Biorepository

The National ALS Biorepository differs from other biorepositories because it does not limit who can take part to a specific area, study, or clinic. The Biorepository samples can be linked with the data on risk factors collected by the Registry. Samples from other studies have been used to find new genes associated with the risk for getting ALS. This Biorepository will also add to the number of samples available for research.



How to Take Part

You must be enrolled in the National ALS Registry to take part in the Biorepository. Only PALS who indicate an interest in the Biorepository will get an information packet. After you agree to get more information, you will need to provide your mailing address and phone number. The Biorepository will try to include as many PALS who want to take part as possible.

ALREADY ENROLLED?

Log into your Registry account and update your account.

NOT ENROLLED?

Visit the Registry website www.cdc.gov/als and create an account.

How It Works

WHAT MAY BE COLLECTED

In-home – blood, saliva, urine, hair, or fingernail clippings

Postmortem – brain, spinal cord, cerebral spinal fluid (CSF), pieces of muscle, bone, and skin

HOW IT'S USED

Samples collected will be used for future ALS research. Researchers need to apply and have their research approved by ATSDR.

