The National Amyotrophic Lateral Sclerosis (ALS) Biorepository

CDC ATSDR

The National ALS Biorepository (Biorepository) is part of the National ALS Registry (Registry). It includes biological samples from persons living with ALS who are enrolled in the Registry.

Purpose of Biorepositories

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 RNA. Some survey data (e.g., demographic, environmental exposure, ALSFRS-R) may also be stored along with a written consent form.

The Importance of this Biorepository

The National ALS Biorepository is important to ALS research because it does not limit participation to a specific area, study, or clinic. The Biorepository provides samples for researchers to use. What makes the National ALS Biorepository unique is the ability to link risk factor survey data from the Registry to samples collected from the Biorepository. This helps create a more complete picture of the disease.

How It Works

What May Be Collected

Blood, saliva, urine, hair, or fingernail clippings

How It's Used

Samples collected will be used for future ALS research by researchers whose studies are approved by ATSDR.

Scan for more information.

How to Take Part

You must be enrolled in the National ALS Registry to take part in the Biorepository. Only people with ALS 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 aims to include as many people with ALS who want to take part as possible.

Already Enrolled?

Log into your Registry account and update your information.

Not Enrolled?

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

Learn more at **cdc.gov/als** or call **(855)-874-6912**