About Us

Our study team is made up of Stony Brook University Hospital neurologists, anesthesiologists, scientists and nurses, all focused on designing better diagnostic tools and therapies for people with ALS.



Ask your doctor to learn more

Drs. Gursoy and Treidler from the Stony Brook ALS Center are members of the ALS-Biomarker study team. They will be happy to council you about your eligibility for the trial.



ALS BIOMARKER STUDY











Collaboration Research Discovery

Privacy

As part of this study we will collect your medical and genetic information. Steps will be taken to protect your privacy and your data. Your data will be deidentified, password protected, and secured in locked facilities. Full privacy disclosures will be reviewed as part of your voluntary consent process. Please direct any privacy related question to the research coordinator.

Contact Us for Information



1 (631) 371-4412



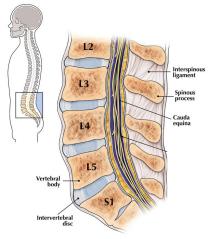
Stony Brook Neurology Clinic 181 N Belle Mead Rd East Setauket, NY



lillian.talbot@stonybrookmedicine.edu joshua.dubnau@stonybrook.edu Understanding ALS is our priority

ALS BioMarker Study

A biomarker is a substance found in the body that can be measured by doctors. We aim to discover RNA biomarkers that will simplify diagnosis of ALS. Ultimately, we hope to improve treatment options for people with ALS.



ALS BioMarker Study

Your brain and spinal cord are bathed in fluid known as cerebrospinal fluid or CSF. Because this fluid contacts the part of the nervous system that is damaged in ALS, biomarkers may be present here that cannot be detected in the blood. Identifying these biomarkers may help doctors to diagnose and treat ALS. To test the CSF, study participants must consent to a lumbar puncture. A lumbar puncture is safe and well tolerated by most patients. Participants will also donate a small blood sample for DNA genetic testing.

Free Genetic Testing Included

Some people with ALS have a genetic mutation that might play a role in their disease. Participants in this ALS Biomarker Research study will have their blood tested for known ALS-related genetic mutations. With your permission, we will return the results of this genetic test to your doctor. You and your doctor will then discuss your results. This service is provided free of charge.



Why Participate in this Study?

- •FREE Genetic testing for ALS genes.
- •Help expand the scientific and medical understanding of ALS
- •Improve ALS diagnostics and treatment for future patients.
- •Learn more about cutting edge genetic research.

How to Participate

1

Call the study coordinator

To join the ALS Biomarker research study or to learn more please call our research coordinator. Lillian Talbot, who will be happy to explain the study to you in further detail and determine your eligibility.

Call 1-631-371-4412

2

Schedule the study procedure

Study procedures are performed at the Neurology Associates of Stony Brook Clinic during a single visit arranged around your schedule. Before the procedure, our study staff will explain the study to you again. We will ask you to read a consent form and then provide written or oral consent to participate. The study visit will take about one hour. We will call to check on you 24-hours after the study.

3

What will it cost?

Participation in the study is voluntary and will cost you no money. Genetic testing of known ALS-associated genes will be performed for all participants with ALS for free. With your permission, the results will be returned to your doctor for you to review together.