Amyotrophic Lateral Sclerosis: Modifiable Barriers to Enrollment in American ALS Research Studies

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By Richard S. Bedlack, Paul Wicks, James Heywood & Edward Kasarskis

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Modifiable Barriers to Enrollment in American ALS Research Studies

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As part of an effort to enroll more ALS patients in a study carried out in collaboration with MGH and the Northeast ALS Consortium we attempted to understand why patients who failed to participate chose not to. We found that ALS patients frequently misunderstood the research process, for instance believing that a blood sample given for a routine lab test would automatically be reused for genetic discovery.

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