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The logo for PRIZE4LIFE, with "PRIZE" in a thin, outlined font and "4LIFE" in a solid red font.



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## Welcome to the **P**ooled **R**esource **O**pen-Access **A**LS **C**linical **T**rials Database

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## How to Use PRO-**A**CT

- Ethical statement for PRO-ACT
- Basic information
- How to use the data dictionary
- Family and Medical History
- Demographics
- Subject ALS history
- Symptoms and outcome measures (FVC, SVC, ALSFRS and Survival)
- Vital signs
- Lab data
- The Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS)
- Concomitant Medication Use
- Adverse Events

### **Ethical statement for PRO-ACT**

In all of the trials that generated the data included in this database, study protocols were approved by the participating medical centers and all participating patients gave informed consent. De-identified data from these trials were donated to the PRO-ACT database for research purposes only and under the explicit conditions that Prize4Life and all users of the data would maintain the anonymity of subjects and not attempt to discover the identity of any subject. In the rare cases where donated data was not already completely anonymized, donated data was further anonymized following the HIPAA de-identification conventions for personal health information: any potential patient initials and/or dates of birth were removed, new randomized subject numbers were created, and wherever possible, trial-specific information was removed in the merging of datasets, including trial center identity and location, trial dates, or other identifying information.

### **Basic information**

Amyotrophic lateral sclerosis, or ALS (also known in the US as Lou Gehrig's Disease and as Motor Neuron Disease in the UK) is a disease that involves the degeneration and death of the nerve cells in the brain and spinal cord that control voluntary muscle movement. Death typically occurs within 3 - 5 years of diagnosis. Only about 25% of patients survive for more than 5 years after diagnosis.

PRO-ACT includes information from over 8500 ALS patients who participated in industry clinical trials. The data is de-identified to protect patient privacy. Different types of information may be available for different patients because multiple trials were merged to create PRO-ACT. Some patients received placebo treatments, while others received experimental treatments (medication), however the medications tested in these specific trials were found to be no better than placebo with respect to their effects on ALS progression.

For every type of information available there is a data file and a dictionary file. Each subject is identified by a SubjectID and the specific assessment for this subject is identified by a record (each subject has multiple records). The assessments are separated into different files according to type:

- ALSFRS(R)
- Death Report
- Demographics
- Family History
- Forced Vital Capacity

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