Clinical Trials Medical Records and Information Checklist

Clinical trials require information about you to help determine whether you are eligible for the trial. We have made a list of the information most commonly required to help you feel prepared. While you may not need all of this information, having it ready can sometimes help speed up your screening time. This information can be gathered by your healthcare provider(s) or yourself depending on the information. While you may need to collect the majority of this on your own, make sure you ask your provider who you can contact at their office about medical records or information to expedite this process.

Self-Reported Data:

- ❑ The date your symptoms began, also known as symptom onset.
- ❑ Relatives who have had ALS, if any.
- ❑ A description of how your symptoms first started.
- ❑ Your ALSFRS-R score. Note: This score is often not easily retrievable. Keep track of these on your own.

Tests and Dates:

- ❑ The date of your ALS diagnosis.
- ❑ The results of your genetic testing, if applicable.
- ❑ MRI results.
- ❑ EMG results.
- ❑ Summary notes from neurologist visits.
- ❑ Slow Vital Capacity (SVC) or Forced Vital Capacity (FVC) number.
- ❑ Overnight Pulse Oximeter results.
- ❑ Complete blood count (CBC) lab results.
- ❑ Any comorbidities you may have. Comorbidities are any other health conditions you have been diagnosed with.
- ❑ A list of all the medications and supplements, including vitamins, herbs, minerals etc. that you take.

Write down other documents that a clinical trial you're considering needs:

1.

2.

3.

4.

5.

I AM ALS does not provide medical advice. Please discuss questions and decisions related to your diagnosis and medical care with your health care team.