

Checklist of Questions To Ask About a Specific Clinical Trial



While there are currently no cures for ALS, there are numerous clinical trials underway right now with the goal of finding safe and effective therapies. Once you and your care team have identified a clinical trial that is right for you, consider asking your trial team the following questions in order to learn more about the logistics, from trial-related costs to privacy information to how samples associated with the trial are handled.

There is often a lot of information to absorb during a trial or site visit. Screenings are typically done in person, but sometimes they are done over the phone, email or a tele-visit. Ask a family member or friend to take notes for you, and ask your trial team whether you can record your visit so you can listen to their answers and advice again at a later time.

Clinical Trial Name:

Clinical Trial Site:

Trial Coordinator Name:

Trial Coordinator Contact Information:

1. Do I need to be patient at this clinic/hospital in order to participate in this trial? If yes, what does that entail?

2. What will be required of me in this trial? Can I participate remotely?

3. What kinds of treatments, tests, scans, and other procedures will I have during the clinical trial? How often will they be conducted? Are any of them optional?

4. What biomarkers are you looking for to satisfy your end point? Will these be tested for in the clinical trial?
5. What is this investigational therapy intended to do for people living with ALS? What are the risks associated with this investigational therapy?
6. How long will the trial last?
7. What, if any, are the out-of-pocket costs associated with participating in this trial? Will the sponsor cover any costs such as travel, lodging, child care, compensation for my caregiver who is taking time off of work, etc.?
8. Will I be able to continue the standard or care treatments for ALS, such as Riluzole and Radicava while participating in this trial? What supplements will I not be able to take during the trial?
9. Will I have access to the therapy once my participation concludes and/or after the trial is completed through Open Label Extension?
10. Can I have a copy of the data you gather on me such as genetic test results among others?
11. What happens to my samples (e.g. CSF, bone marrow) after the trial? Do you have a biorepository center that I can donate my samples to for your research? If not, can you send my samples to a biorepository center of my choosing?

12. Are you sharing this data with other researchers? Also, are placebo results being shared with [PRO-ACT](#)?

13. What happens if I am not approved to participate in this trial? Are you screening for other trials that I would qualify for?

Write down other questions you have:

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.