

## 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 - take a family member or friend with you who can take notes 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:** .....

**Trial Coordinator Name:** .....

**Trial Coordinator Contact Information:** .....

**Date:** .....

1. What will be required of me in this trial?

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2. Will the clinical trial's research team work with my care team while I am in the trial? If yes, how?

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

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4. What is a biomarker? Will these be tested for in the clinical trial?

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5. How will participating in this clinical trial benefit me? What are the risks?

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6. Can I participate in this trial remotely?

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7. How long will the trial last?

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8. What are the 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.?

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9. Will insurance cover any trial-related costs?

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10. Will I be able to continue my current treatments or medications, such as Riluzole, Radicava or supplements, while participating in this trial?

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11. Can I opt out of the trial once I have started it?

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12. Will I have access to the therapy once my participation concludes and/or after the trial is completed?

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13. How will my safety and privacy be protected?

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14. May I have a copy of the data you gather on me?

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15. 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?

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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.*

