Start the Conversation
Here are several questions to discuss with your Rett clinic team or clinical trial site as you consider enrolling in a clinical trial.

1. What is the purpose of the clinical trial?
2. Why do researchers think that this particular Rett syndrome treatment might work?
3. Who is paying for and supporting the study?
4. Who has reviewed and approved the study?
5. Who will be in charge of my loved one’s care?
6. How will the trial benefit my loved one or others?
7. How long will the study last?
8. How is the treatment given (e.g. orally, as an injection, etc.) and how often must it be taken?
9. What will my responsibilities be if my loved one participates?
10. What kinds of tests will be involved? How will data be collected (e.g. blood sample, behavior observation)?
11. Do I need to stop any physical therapies or other interventions my loved one with Rett syndrome is receiving?
12. What are the possible risks, side effects, and benefits?
13. Can I talk to other people who are participating in the study?
14. Will I be compensated for my participation in the clinical trial and my travel expenses?
15. What is the time commitment for me? How many times will I have to visit the trial center? How long will each visit be?
16. Will results of the clinical trial be made public and, if so, when?
17. With whom should I communicate during the trial: the research team, my Rett syndrome care team, or both?
18. When will I find out if my loved one received a placebo or the experimental treatment during the clinical trial?

Learn more at trials.rettsyndrome.org