

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