

QUESTION PREP FOR CLINICAL TRIALS



It's important to be well-informed about your participation in a clinical trial. Use this informational sheet to help ask important questions prior to enrolling in a clinical trial for Krabbe disease.

QUESTIONS FOR THE PRINCIPAL INVESTIGATOR:

1. How many participants have enrolled in this clinical trial thus far?
2. What is the total time commitment to participate in the clinical trial from start to end?
3. What's the mean age of the participants enrolled in this clinical trial?
4. What other treatments are utilized for Krabbe disease?
5. What types of long-term benefits are expected for participants?
6. Does participation in this trial disqualify participants from other clinical trials and/or treatments?
7. What expenses will or will not be covered for participants in this clinical trial?
8. Will we need to relocate and if yes, are those costs covered?
9. What follow-up visits and tests will be required for participants in this clinical trial?
10. Will we receive a stipend for our participation in this clinical trial to help offset out-of-pocket costs?
11. What are the risks and side effects of the treatment. How many participants experience the side effects?
12. Who will have access to participant information due to our enrollment in this clinical trial?
13. Will we receive copies of information collected in this clinical trial? For example, results from genetic testing, copies of MRI's, developmental testing, clinical trial outcomes, and more.
14. How do you partner with local doctor/s to ensure participants receive necessary support upon return of home?
15. Are participants allowed to be removed from the clinical trial at any point in time?