children & CLINICAL STUDIES

Questions You Should Consider Asking

There is a lot of information that is provided when thinking about enrolling in a clinical study, but you may have more questions. Here is list of possible questions you might want to consider asking your research team. Remember that you should ask questions until you are comfortable with the information provided.

The Study

1. Why is the study being done?
2. Why do researchers think the approach may be effective?
3. Who is paying for and supporting the study?
4. Who has reviewed and approved the study?
5. How are study results and safety of participants being checked?
6. How long will the study last?
7. What will our responsibilities be if we participate?

Possible Risks and Benefits

1. What are the possible benefits?
2. What are the short-term risks, such as side effects?
3. What are the possible long-term risks?
4. What other options do people with similar conditions have?
5. How do the possible risks and benefits of this trial compare with other options?

Participation and Care

1. What kinds of therapies, procedures or tests will my child have during the trial?
2. Will they hurt, and if so, for how long?
3. How do the tests in the study compare with those my child would have outside of the trial?
4. Will my child be able to take his or her regular medications while in the clinical trial?
5. Where will my child have his or her medical care?
6. Who will be in charge of my child's care?

Notes:

Personal Issues

1. How could being in this study affect the daily life of my child or my family?
2. Can I talk to other people in the study?

Cost Issues

1. Will I have to pay for any part of the trial such as tests or a study drug?
2. If so, what will the charges likely be?
3. If I have health insurance, what is it likely to cover?
4. Who can help answer any questions from my insurance company or health plan?
5. Will there be any travel or child care costs while my child is in the trial?

Tips for Asking your Doctor About Trials

When you talk with your doctor or members of the research team:

1. Consider taking a family member or friend along, for support and for help in asking questions or recording answers.
2. Plan ahead what to ask – but don't hesitate to ask any new questions you think of while you're there.
3. Write down your questions in advance, to make sure you remember to ask them all.
4. Write down the answers, so that you can review them whenever you want.

Source: Modified from NCI/NIH, http://www.cancer.gov/clinicaltrials/learning/questions-to-ask-about-participating

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