Should My Child Participate?

Helping you make an informed decision about your child’s participation in a clinical study.

Key questions to ask:

GENERAL QUESTIONS:
- What is the purpose of this clinical study?
- What is my child expected to do as a volunteer?
- Will we be able to see my child’s doctor?

COST:
- Will I have to pay for any part of my child’s clinical study? If so, will our insurance cover these costs?
- Will I be reimbursed for travel costs? for parking? for meals?

TIME:
- How many visits to the study center are required and how often are the visits?
- How long will each visit take?

SAFETY:
- What are the possible risks for my child in participating for this study?
- What undesirable event or other type of discomfort has to happen for my child to be removed from the clinical study? If that happens, will some alternative therapy be offered?
- Will my child receive any follow-up care after the clinical study has ended?
- Who will know that my child is participating in a clinical study?

For answers to additional questions, visit our website at www.CISCRP.org or call 1-877-MED-HERO.

CISCRP – helping you to make an informed choice
What is a pediatric clinical study?

A pediatric clinical study is also known as a “clinical research study”, a “research study”, or a “clinical trial”, and aims to answer specific questions about children’s health.

A pediatric clinical study is conducted according to a plan called a protocol, which describes:

- What types of volunteers may enter the study
- The schedules of tests and procedures, study medications and dosages
- Length of the study
- Number of study visits

The parent(s) or guardian of each child volunteer participating in the clinical study must agree in writing to follow the protocol. This is called giving informed consent.

Participating in a clinical study is voluntary, and your child may decide to stop participating for any reason, at any time.

Things toConsider Before Volunteering

A clinical study is also known as a ‘clinical research study’, or a ‘clinical trial’, and aims to answer specific questions about your health and wellness. BEFORE TAKING PART in a clinical trial, certain information should also be considered:

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What are some possible benefits of my child’s participation?

- You and your child may help others by contributing to medical research and treatment advances
- Your child will receive study-related medical care for the condition being studied

What are some possible risks of my child’s participation?

- Your child’s study medication, therapy or device may not be effective
- There may be unpleasant, serious, or even life-threatening side effects as a result of the study medication, therapy or device
- Your child’s participation in the clinical study may be time consuming

To help you decide if your child should participate in a clinical trial, ask questions, search the library or Internet for information (See Learn More About Clinical Trials on back), and seek the advice of family members or a trusted doctor, clergyman or friend.

Remember, your participation in clinical trials is strictly voluntary and you can drop out at any time for any reason.

CISCRP is not involved in recruiting patients for clinical studies, nor is it involved in conducting clinical studies.

Where Can I Go For Help?

GENERAL RESOURCES

Search Clinical Trials - A public service that compiles clinical study listings | www.SearchClinicalTrials.org 1-877- MED HERO

CISCRP - Resources to help you make an informed decision about your child’s participation | www.CISCRP.org 1-877-MED HERO

ClinicalTrials.gov - a registry of federally and privately supported clinical studies conducted in the United States and around the world. | www.ClinicalTrials.gov

CenterWatch - Clinical study information and listing service. Includes pediatric and neonatal studies. http://www.centerwatch.com/clinical-trials/listings/ 1-866-219-3440


Visit CISCRP.org for more information, including disease and condition specific resources.

“Education Before Participation”

“Should My Child Participate” is part of CISCRP’s Education Before Participation resource series. An editorial panel of patients, public and professional representatives has reviewed this educational brochure.