

Children & Clinical Studies—New NIH Website For Parents Helps Answer Questions

(NAPS)—For those who have ever wondered about enrolling children in a medical study, here's some encouraging news. Research in children—on everything from cancer to premature birth—helps save lives and improve children's health. Although it is vital to conduct research studies in children, families frequently hesitate to have their children participate. They have questions and concerns and, in some cases, are not even sure what to ask.

To help families and others interested in this issue, the National Heart, Lung, and Blood Institute (NHLBI), part of the National Institutes of Health (NIH), has launched a new website at www.ChildrenAndClinicalStudies.nhlbi.nih.gov. The site addresses the importance of conducting research in children and the most common questions posed by families. It was developed in conjunction with the New England Research Institutes (NERI), with partial funding from other NIH components and the National Marfan Foundation (www.marfan.org).

The website features videos of children who are in a variety of clinical trials and their parents. They talk about why they are in the studies and how their concerns were addressed.

The website notes that treatments for children are often based on what works in adults. This "hand-me-down" approach is not ideal, say some experts, because children "are not little adults." They are unique, particularly when it comes to their medical needs.

The website also includes:

- Why research is important, how being in a study differs from receiving routine medical care,



Caroline, 10, is in the Marfan syndrome clinical trial.

and how studies are designed and monitored to protect participants;

- Information on the research team, what you might need to ask, and the role kids play in participating;

- How studies affect the family, plus what happens if you leave a study or when the study ends;

- Your rights, where to find more information and terms that you may hear in a study.

"We hope this new resource will help parents learn more about how clinical studies are conducted in children so they can make well-informed decisions," said Elizabeth G. Nabel, MD, director of NHLBI.

Kathleen McNeill's 10-year-old daughter Caroline is in a study comparing two treatments for a potentially life-threatening disorder called Marfan syndrome. Kathleen encourages other parents to consider enrolling their children in research. But, she says, "If you don't feel comfortable, get more information and ask questions, so you can make an honest decision about what you're going to do."

Did You Know?

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