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## Pediatric Clinical Studies



Participating in a Pediatric Clinical Study is a very personal decision that is unique to every family. The first step for caregivers in making an informed decision about enrolling their child within a clinical study is to educate and empower themselves. Knowledge is a remarkable tool.

The following information is presented in partnership with the [National Institute of Health \(NIH\) Children and Clinical Studies](#) Campaign.



[For Caregivers: A documentary on  
Pediatric Clinical Studies.](#)

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How will my child benefit?

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## How Will My Child Benefit?



A frequent question caregivers ask is, “How will my child benefit?”

In addition to receiving access to new drugs or treatments, children and caregivers are participating in something to make an impact across the globe. Children in Pediatric Clinical Studies are assisting in the advance of treatments and providing knowledge to potentially help future generations.



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Why is Research with  
Children Necessary?

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## Why is Research with Children Necessary?

*“To continue to do research in children says to us as a society that our children are important and we value them.”* Vicki Pemberton, RNC. MS, Research Nurse

Many drugs prescribed for children are based on research from adult clinical studies and physicians are challenged with adjusting the dosage for children. Approximately 70% of medications prescribed for children have not been tested with children.

As we know, children are not little adults. Pediatric Clinical Studies help provide vital data so that children can be treated based on their developmental needs – both brain and physical.

One size does not fit all. Research with children assist in uncovering the most effective therapies for infants, children, and adolescents.



[Learn more about research  
with children.](#)



[Learn why clinical studies are  
important.](#)

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[How Do Kids Feel About  
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## How Do Kids Feel About Clinical Studies?

Children are the center of any pediatric clinical study and it's essential for the Research Team, caregivers, and extended family to hear their voices.

Including them in the conversation helps children be a part of their clinical study, not just in it. And depending on their age, these pediatric clinical study participants will have *a lot* to say!

It's important to foster an environment where children feel comfortable asking questions, talking about how they are feeling, and voicing any concerns. An open line of communication truly empowers children.

Hear first-hand what children are saying about being in study in the video below.



[Learn more about what children are saying  
about Pediatric Clinical Studies.](#)

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Keywords You  
Should Know

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## Keywords You Should Know

An important part of any Pediatric Clinical Study is understanding the terms and their meanings used in conversation with you, your child, and family members.

*Placebo*, *informed consent*, and *protocol* are just a few clinical study words that may be brand new to your vocabulary. If at any time you hear something that you're not familiar with, don't hesitate to ask what it means.

Watch the video below for a summary of common terms used in clinical studies.

[Explore common clinical study terms.](#)

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[Your Clinical Study Team](#)

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## Your Clinical Study Team

Every Pediatric Clinical Study has its own Research Team. These team members can include doctors, nurses, research scientists and coordinators, and pharmacists. The number of team members will vary depending on the size of the clinical study in which your child participates.

Your child's research team works in close partnership with you and your child. Research Team members provide medical care in an ethical, legal, and safe way. They also serve as part of an extended support system for children and their families.

[Get to know each Research Team member's role.](#)*Or explore the next topic*

Questions to Ask



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## Questions to Ask

Asking questions empowers caregivers. Take as much time as necessary to speak with doctors and members of the Research Team in order to make an educated decision on your child participating in a Pediatric Clinical Study.

Questions such as “What is the length of the study?”, “What are the potential benefits and risks?”, and “Is there a cost involved?” are just a few of the important details caregivers need to know. For a comprehensive guide of potential questions to ask, please [visit here](#).



- Come prepared with your list of questions and concerns.
- Bring a family member/friend for support and help with note taking.
- If something is not 100% clear, keep asking until it’s understood.

[Access a printable “Questions to Ask” form here.](#)

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Rights of Study Participants



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## Rights of Study Participants

Each and every child participating in a clinical study has a “patient bill of rights”. It’s important for caregivers to know about and understand the rights put in place for their child. Caregivers and their children have the right to be fully informed on what occurs before, during, and after a pediatric clinical study.

[Learn more on the rights of children and their families in a Pediatric Clinical Study.](#)

## You Can Say “No” At Any Time



Participation in a pediatric clinical study is voluntary. You can withdraw your child from the study at *any* time and for *any* reason. The care your child receives will not change or be influenced by your decision to say “no”.

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