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## How does research help?

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The care a child gets today is based on what has been learned from previous care and research studies. Research helps healthcare providers learn more about children and the care they need.

Research done in the Pediatric Cardiac Sciences Program has shown:

- that babies under 1 can get a heart transplant from a donor with any blood type (this has saved many lives)
- that 3D echocardiograms are a non-invasive way to look for heart disease in children (this has helped plan and evaluate many heart valve surgeries)
- how to reduce hearing loss in children with heart problems

Research done through the program has also helped develop:

- a Fetal Cardiology program, which is now a Western Canada referral centre
- prototypes for 2 heart catheters, which are used in Canada, USA, and Europe
- world-class heart surgery and intensive care with outcomes in the top 5 percent of North America

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## Are there protections to keep my child safe?

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The goal is to do research without your child being exposed to unneeded risks. All research in the hospital has been reviewed and approved by Alberta Health Services and the University of Alberta Faculty of Medicine and Dentistry.

To make sure studies are well designed with minimal risks, they are reviewed in detail and need advanced approval from:

- an internal review board in the pediatrics department at the University of Alberta
- the Research Ethics Board, which is made up of doctors, scientists, and lay people

Some studies may also need other reviews and approvals (e.g., Data and Safety Monitoring Board) to follow the study results and stop it if risks are higher than expected.

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## Contact Information

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Pediatric Cardiac Sciences Program  
Stollery Children's Hospital  
University of Alberta  
8440-112<sup>th</sup> Street  
Edmonton, Alberta T6G 2B7  
Phone: 780-407-3952  
Fax: 780-407-3310

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## Websites

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[www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca)

For information on medical research and children, go to [www.kidsemedtv.com/kids-video.html](http://www.kidsemedtv.com/kids-video.html)

For 24/7 general health information or nurse advice, call Health Link Alberta at 1-866-408-LINK (5465) toll-free.

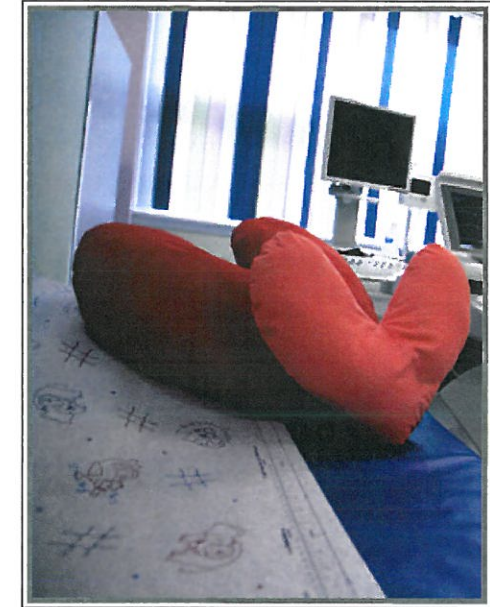
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*This material is for information purposes only. It should not be used in place of medical advice, instruction, and/or treatment. If you have questions, speak with your doctor or appropriate healthcare provider.*

health information

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# Cardiac Research and Your Child



**The Stollery Children's Hospital and the University of Alberta are committed to clinical excellence.**

**You can help.**



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## **What is medical research?**

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Medical research is an organized way to learn about health and find better ways to treat children's illness and disease. Medical research is often called a study or a clinical trial. The goal of the research is to answer a question that will improve care.

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## **How can my child help?**

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Research is done to learn if there are new or better ways to treat babies and children with heart problems. Participating in a medical research project may not benefit your child at the time, but what is learned will help children with heart disease to get the best, most up-to-date, quality care.

While your child is at the Stollery Children's Hospital, you might be asked to think about taking part in one or more research studies. These studies might be done by heart specialists, surgeons, or other healthcare providers in the Pediatric Cardiac Sciences Program.

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## **If my child is eligible for a study, what happens next?**

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If your child is eligible for a study, a healthcare provider from the research team will:

- talk to you about the study
- give you an information sheet
- answer your questions
- ask you to sign a consent form
- tell you how to contact the research team and the University of Alberta Research Ethics Office

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## **Is medical research different from the medical treatment my child gets?**

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Although the place and doctor might be the same, there are some differences between medical treatment and medical research.

*Medical Treatment:* The goal is to treat a specific child for a certain type of illness or injury. The treatment is adjusted to meet the child's needs.

*Medical Research:* The goal is to improve therapies for all children by learning more. Treatment follows a certain study design or protocol and is not adjusted unless there are safety concerns. In some studies, your child might only be observed with no changes to medical treatment at all.

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## **How do I decide?**

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Before you decide, think about or ask these questions:

- What are the risks and benefits of the study? How likely are the risks? How will risks be decreased? How will my child's safety be monitored?
- Am I comfortable with my child doing the activities in the study? Is there likely to be any discomfort?
- Am I comfortable with the time commitment? How many visits are involved and when will they be?
- What will my role as a parent be? Will I have to monitor anything or do any paperwork?
- How will I feel if my child doesn't get the experimental treatment?
- Am I interested in the goals of the study?

You may want to talk with friends, family, or a doctor who is part of the study (or one who isn't) to help you decide. You can take as much time as you need to think and talk about the study before making a decision.

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## **Why do I sign a consent form?**

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When you sign a consent form, it shows that you understand and give permission for your child to be in a study. You will get a copy. Your child might also get a form to sign. You can ask the research team to tell your family doctor about any study your child is a part of.

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## **What if I don't put my child in a study?**

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Your child will always get the best care, even if you choose not to be part of a research study.

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## **What if I sign the consent form and then change my mind?**

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Even if you sign the consent form, you can change your mind at any time. All you have to do is contact someone from the study team at the phone number listed on the information and consent forms. Ask to have your child's name removed from the study.

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## **Do I have the right to say no?**

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Yes. Research involving your child will only happen with your knowledge and permission. Medical research is not for everyone. There is no right or wrong answer. You need to do what is right for your child and your family.