

## IS IT SAFE TO PARTICIPATE IN RESEARCH?

All research studies must be conducted according to strict guidelines and regulations that are designed to protect the rights and well-being of you and your child. These rules are set out by groups such as Health Canada, the U.S. Food and Drug Administration, Research Ethics Boards, and Hospital Review Committees. Clear and strict rules help increase the chance that the benefits of participating in a study outweigh any possible risks.

There are always risks and unknown things in research. Side effects or unfavorable reactions to medications, vaccines, or treatments can occur and depending on the study, your child may receive treatment that is not effective for their condition. However these same risks are not uncommon during daily life. For example, with any new medicine or food that you give your child there is always a chance they may have an allergic reaction or that the medicine may not work for them.



Participation in clinical trials and medical research is completely voluntary. It is a personal choice that must be made carefully by parents and children, and there is no “right” or “wrong” answer. We recommend you take time to review all the information that is provided to you. We encourage you to consult with your family, friends, and doctor.



## SHOULD MY CHILD PARTICIPATE IN A RESEARCH STUDY?



## WHO CAN I CONTACT FOR MORE INFORMATION?

The Clinical Research Unit at the Manitoba Institute for Child Health has a team of skilled professionals who can help answer your questions about child health research.

### Clinical Research Unit

John Buhler Research Centre, Room 511  
715 McDermot Avenue Winnipeg MB R3E 3P4  
Phone: 204.789.3206 Email: [cru@mich.ca](mailto:cru@mich.ca)

To find out more about the Manitoba Institute of Child Health and for a list of current clinical research studies, please visit [www.mich.ca](http://www.mich.ca) or call **204.789.3447**

**Deciding whether to let your child participate in a research study or clinical trial is an important decision. This information pamphlet is written for parents and families to help answer your questions about health research and help you make an informed decision that is right for you and your child.**

### **WHAT IS CLINICAL RESEARCH?**

The terms clinical research, clinical trial, and research study can all be used to describe health research. Research helps us learn more about health in general, and helps find better ways to prevent and treat disease and illness. Research studies can involve children of all ages, from premature babies to teenagers, and can include sick or healthy children.

### **WHY IS CHILD HEALTH RESEARCH SO IMPORTANT?**

New discoveries and advancements in child health are the results of research. By doing research, we are able to identify which procedures and treatments work best and which doses of medication are safe and effective in children. It also helps us find the underlying causes of disease and can help prevent kids from getting sick.

Children are not little adults and often don't respond to medical care the same way that adults do. Some illnesses and conditions are only seen in infants and children. Research needs to involve children so that doctors can know how to best care for kids.

Treatments for children must be tested in children, just as treatment for adults must be tested in adults. Until recently, between 70 and 80 percent of medicines used in children were never tested in children. Today, it is increasingly recognized that children have the right to research that meets their unique needs.

Child health researchers are also taking up the challenge of finding the earliest causes of adult disease - many of these are present in childhood. By understanding and addressing the earliest signs of these conditions in children, researchers work so that future generations can live healthier than ever before.



## **CHILD HEALTH RESEARCH SUCCESS STORIES**

**We are living longer and healthier thanks to research.** The twentieth century saw the human life span advance in many countries because of research that helped battle childhood infectious diseases and early childhood malnutrition.

**Childhood diseases that used to kill are a thing of the past.** As recently as 40 years ago, children were dying from diseases like polio, mumps, and measles. Today, kids no longer have to suffer from these illnesses because of researchers who developed vaccines and parents who decided to put their kids in studies to test these new vaccines.

**More children are winning their battles with cancer.** Almost every child in the developed world who is diagnosed with cancer participates in research studies. This has led to significant advances in the way doctors treat childhood cancer. Now more kids than ever before are surviving cancer.

### **WHAT IS REQUIRED IF WE AGREE TO PARTICIPATE?**

Each research study will have different requirements. The purpose of the study will be clearly explained beforehand so that you understand what the research team hopes to learn and what you and your child will need to do.

Some studies may involve filling out surveys or questionnaires, while others may involve taking medications, getting a vaccine, eating a special diet, or using a new device. Some studies may require multiple tests (blood, urine, x-ray, MRI) and repeat visits to the research clinic. Other studies may require little testing and fewer visits. The time commitment required from participants will vary depending on the study.

### **WHAT ARE THE POSSIBLE BENEFITS OF PARTICIPATING IN RESEARCH?**

- You and your child can help researchers learn new things that could benefit your child as well as future generations.
- You and your child may gain access to the latest treatments and medications available, and learn new information about your child's condition.
- You and your child will receive personalized attention and individualized care. Your child's medical care will be monitored by research staff to ensure that care plans are followed exactly.
- Certain studies may pay participants for their time and additional expenses associated with research.

