## SHOULD I TAKE PART IN A RESEARCH STUDY?

Thousands of research studies are being conducted each year. These research studies have contributed to health improvements for many people from every walk of life.

None of the advances in health care would be possible without people willing to volunteer to take part in research study. This pamphlet aims to help you understand your rights as a research study volunteer. It will help you to decide if you should take part in a research study. It will try to help you understand some of what is needed for a good research study. We urge you to review this information and discuss it with other people you trust.

### WHY IS RESEARCH IMPORTANT?

Research has led to important discoveries that make our lives better. Some examples are:

- New drugs to treat diseases
- Ultrasound, x-ray machines, and diagnostic tests
- Ways to lose weight
- Improved medical procedures

# WHO WILL ANSWER MY RESEARCH QUESTIONS?

The research team will explain the study to you. The consent form includes this explanation. If you have any questions, ask the research staff. If you don't understand something, ask them to explain it to you so you do understand. You can take the information home. You can discuss it with your family, friends, a health care provider, or others before you decide whether or not to take part in the research study. If you decide to take part in the research study, you will be asked to sign the consent form.

The informed consent process is more than just signing a piece of paper. It is a process that goes on throughout the research study. During the research study, you may be told of new findings, benefits or risks. At that time, you can decide whether or not to continue to take part in the research study. You may decide not to take part. You may change your mind and leave the research study before it starts. You may also leave at any time during the research study or the follow-up period.



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# HUMAN RESEARCH PROTECTION PROGRAM

PENNINGTON BIOMEDICAL RESEARCH CENTER

Rights, Responsibilities, Benefits, and Risks of Human Research Study Participation

Human Research Protection Program Office 6400 Perkins Road Baton Rouge, LA 70808 225-763-2693 irb@pbrc.edu



## WHY SHOULD I VOLUNTEER FOR A RESEARCH STUDY?

There are many reasons to participate in research study. You may want to:

- Help find a cure for an illness
- Help other people who are sick
- Help find ways to provide better care
- Help scientists find out more about how the human body and mind work
- Take part in a research study that is trying to find a better treatment for a condition that you have.

If you decide to take part in a research study, you do so as a **VOLUNTEER**. That means **YOU** decide whether or not you will take part.

If you decide to participate, someone from the research team will explain the details of the study to you. Information must include the following:

- The purpose or goals of the study
- A description of the study
- Exactly what your participation involves (the exact tests and procedures you will be required to go through, and the amount of time the study will take)
- The known risks and benefits of participation

#### **CAN I CHANGE MY MIND?**

Yes. If you decide to be in a study now and you change your mind later, that is your right. You just have to notify the study doctor or the study staff as soon as you change your mind. They may ask you to come back for a final visit to check your health.

# INSTITUTIONAL REVIEW BOARD (IRB)

Human subjects research at Pennington Biomedical Research Center is reviewed and approved by an Institutional Review Board (IRB). The IRB includes medical people, scientists, and people from the local community. They review human research to make sure it is well-planned and ethical. The IRB serves to protect your rights and your welfare before and during the research study.

# ARE THERE BENEFITS TO BEING IN A RESEARCH STUDY?

There may or may not be a direct benefit to you if you take part in a research study. For example, your health or a health condition you have may get better as a result of your participation in the research study. It may stay the same. It may get worse. No one can predict what will happen with a research study or how it might affect you. The research study may not help you personally. The research study may result in information that will help others in the future.

#### **QUESTIONS TO ASK**

- What exactly will happen to me in the research?
- Will there be any unpleasant side effects?
- Will the research help me personally?
- What other options do I have?
- What tests or procedures will be done?
- Is it possible that I will receive a placebo (inactive substance)?
- What could happen to me, good and bad, if I take part in the research?
- How long will this research study last?
- What will happen to any specimens that I give?
- Will I receive compensation for participating in his research study?
- Will I be told the results of the research study?