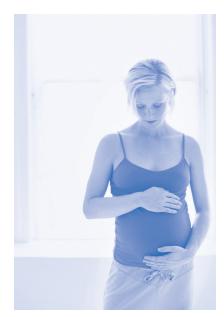# Questions and Answers

About the Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)

One in every 33 babies in the United States is born with a birth defect. Birth defects are one of the leading causes of death in the first year of life and can affect how a child's body looks, works, or both. While we know the causes of some birth defects, we do not know what causes most of them. Researchers across the nation are teaming up with the Centers for Disease Control and Prevention (CDC) to find answers through the Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS).

What is BD-STEPS? BD-STEPS is a nationwide effort to find causes of birth defects by collecting information from women who have recently been pregnant. We study many different types of birth defects, including cleft lip, spina bifida, and heart defects.

How does the study work? We talk to women who had pregnancies affected by birth defects as well as women whose pregnancies were not affected by birth defects. We ask about their pregnancy experience and health. We also want to study the role genetic (inherited) factors play in the health of a baby. That is why we ask some mothers to participate in a second part of the study that includes giving approval for us to use a small amount of leftover heel stick blood that was already collected from the baby at birth.

Why do you need information about genes? We hope to study genetic material to see if certain forms of genes are more likely to be present when birth defects occur.

Who funds the study? CDC funds the Centers for Birth Defects Research and Prevention (CBDRP) that work together on the study. Participating CBDRP sites include: Arkansas, California, Georgia (CDC), Iowa, Massachusetts, New York and North Carolina.

How did you get my name? Birth defects are a serious public health concern, and state laws allow each study site to collect information on pregnancies affected by a birth defect. This is how most women are identified in the study. Women whose pregnancies were not affected by birth defects are chosen from women who gave birth in the same year.

What will the results show? Since the study looks at a large group of women, this means findings will apply to "the average woman" rather than any specific individual. There are many possible results. We may uncover:

- Risk factors, things that raise the risk for birth defects
- Protective factors, things that lower the chances of having a baby with birth defects
- Neutral factors, things that neither raise nor lower the risk

What will you do with the study findings? We publish findings in medical journals. Because birth defects are of great interest, findings are often covered in the news as well. We also will publish findings in a yearly electronic newsletter that we will make available to women who take part in the study.

Why is this study so important? Understanding the causes of birth defects can help us prevent them. The size and scope of this study will provide important clues to help us in our journey to ensure that every child is born with the best health possible.

What You Need to Know About Participating

What does the study involve?

1. An interviewer will call you in about one to two weeks to begin the interview or set up a good time for the interview. The interview lasts about 55 minutes, and it can be split into segments to fit your schedule.

2. After the interview is complete, we hope you will participate in more parts of the study. You will receive separate mailings for each part of the study where you qualify.

Where is the study conducted? You can participate in all parts of the study from your home or any private location you choose.

How will the study benefit my family? Study results will not directly benefit you or your family. However, many women feel good about helping to find causes of birth defects.

Are there any disadvantages to participating? Some women interviewed find it emotionally difficult to discuss their pregnancies. There is no other likely disadvantage.

What do I get for participating? We have enclosed a $20 gift card as a token of appreciation for your time and interest. The gift card is yours to keep whether or not you take part in the interview. If you choose to participate in the study, you have a chance to receive more gift cards.

Do I have to participate? No. There will be no harmful effects if you refuse. Your decision will not affect health care services or other benefits you or your family may receive.

What will I be asked in the interview? The interview covers a wide range of topics about you and your pregnancy. Sometimes we ask you to answer in your own words. Other times, we will give you several possible responses to choose from.

We will ask about the following things in your interview: your recent pregnancy and the month before you became pregnant, past pregnancies, your general health, family background, lifestyle, work, and prescription and non-prescription medicines taken. We will also ask a few questions about your baby's father. Please look at the medicine sheet in this packet to help you remember the medicines you took around the time you became pregnant and in your first trimester.

What if I do not want to answer or can't remember? You may skip any questions you wish. It is okay to say that you don't remember. We want you to answer as accurately and honestly as possible.

How will my privacy be protected? We will never use any names in reports or publications. We will not give any information about you to anyone who is not an approved researcher on this study. No one else may look at your data, including insurance companies, even if requested by a court of law. We keep records under lock and key. All computer files are password protected.

Study contact information. If you have any questions, please feel free to call us at our toll free number, **1-888-743-7324** or email us at **questions@bdsteps.org**. You can also visit **www.bdsteps.org** for more information about the study. To reach local researchers, use the following information: