

# Questions & Answers



**national • birth • defects • prevention • study**

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
CENTERS FOR DISEASE CONTROL AND PREVENTION  
Centers for Birth Defects Research & Prevention

# About the Study...

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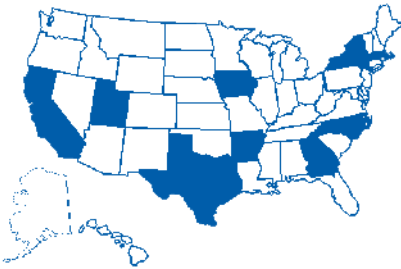
## Why are you studying birth defects?

People are often surprised to learn that birth defects are common, found in 1 in 33 newborns. Most of the time, doctors and scientists do not know what caused them. This study will move us closer to understanding the causes of birth defects and ways to prevent them.

## What is the National Birth Defects Prevention Study?

A nationwide effort to find causes of birth defects.

- Interviews are conducted by 9 birth defects programs called "Centers for Birth Defects Research and Prevention." They are located in Arkansas, California, Georgia, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah.
- About 2,500 women are interviewed each year.



- Many different types of birth defects are being studied. About 1,800 women interviewed yearly will have had children or pregnancies affected by birth defects.
- About 700 of those interviewed yearly are mothers of infants with no birth defects.
- Women interviewed will be sent a cheek cell collection kit to help us compare genetic factors with information given during the interview.
- The study is funded by the Centers for Disease Control and Prevention.

## Why are you interviewing women?

There is no way to recreate the many events and exposures that happen during pregnancy in a lab - only women can give us this information.

## Why do you need information about genes?

The cheek cell samples provide critical genetic information. The interview provides critical information about factors in the environment that may affect birth defects. This study will help us find out how the two interact.

# About the Findings...

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## How do you interpret the results?

- We ask the same questions to all women, whether or not their pregnancies were affected by birth defects.
- We then compare responses between groups.
- We do not look at individual answers; we only consider groups. We calculate averages and other statistics for our analyses.
- We combine data from all centers to perform statistical tests.
- We study genetic material from cheek cells to see if certain forms of genes are more likely to be seen when birth defects occur.

## What will the results show?

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

## Can you give an example of a risk factor?

Cigarette smoking is a risk factor for developing lung cancer. This means that those with lung cancer are more likely to be smokers. While not all smokers develop lung cancer and not all persons with lung cancer are smokers, we know that not smoking helps prevent lung cancer.

Likewise, the same is true for findings from this birth defects study. Having one or more risk factors does not prove what caused birth defects in a particular case. But avoiding those risk factors, if possible, may help prevent future birth defects.

## 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. They may also be used in health education materials. We will also publish findings in a yearly newsletter that we send to women who took part in the study. Remember, all our findings pertain to groups of women; no one will be able to identify you from our reports or publications.

## Your privacy will be protected in the following ways:

- Your answers and any results of genetic tests will not be seen by anyone outside the study.
- Your identity is secret. We will never use your name, the father's name, or your child's name in any report or publication.
- Information about you will not be given to anyone outside the study, including insurance companies or other government agencies, even if requested by a court of law.
- Records are kept under lock and key. Identifying information is removed from computer files, which are password protected.

## To Participate...

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An interviewer will call you in about 2 weeks to set up a convenient time for the phone interview. She will make sure that you understand the most important points about the study, its risks and benefits. These are:

- This is a national study to discover clues about what causes birth defects. It is being conducted in 9 states. It has 2 parts: a telephone interview and a cheek cell collection.
- The interview takes an hour or so. It can be split into several segments to best suit your schedule. It covers a broad range of topics.
- Cheek cell collection consists of rubbing a soft brush inside the cheek. This procedure causes little to no discomfort. The kit will be sent to you in the mail.
- Some women interviewed find it emotionally difficult to discuss their pregnancies. There is no other likely disadvantage.
- Taking part in the study will not benefit you or your family directly. However, the findings may help others prevent birth defects in the future.
- You can choose not to participate. This decision will not affect the care or services that you or your family receives.
- You can choose not to answer any specific questions. You are free to stop the interview at any time.
- You can choose not to provide cheek cell samples.
- All your answers and results of genetic tests are confidential. Your identity will remain private.

# Questions You May Have...

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## **How did you get my name?**

Part of our ongoing work to find causes of birth defects includes studying them when they occur. State law allows us to monitor cases of birth defects. This is how we identified most women in the study. Women whose babies do not have birth defects were selected randomly from women who gave birth in the same year.

## **What does the study involve?**

The study has two parts: 1) a telephone interview at a time convenient for you, and 2) a collection of cheek cells from immediate family members.

## **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.

## **What do I get for participating?**

We have enclosed \$20 with the introductory letter to thank you for your time and inconvenience. The money is yours to keep whether or not you participate in the study. We will send another \$20 with the cheek cell kit. And if you complete both parts of the study, you will get a third \$20 when we receive your cheek cell samples.

## **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 the father. These include your:

- recent pregnancy and the 3 months before you became pregnant
- past pregnancies
- health and diet
- prescription and non-prescription drugs taken
- family background and lifestyle
- work and hobbies

The interviewers ask everyone the same questions in the same way. Sometimes we ask you to answer in your own words; other times, we will give you several possible responses to choose from.

## **Can you not get this information from my doctor or my hospital records?**

No. Most doctors do not routinely ask about the topics we are studying. You are the only one who can supply the information we need.

## **What if I do not want to answer?**

You may skip any questions you wish.

## **What if I can not remember?**

It is OK to say so. We want you to answer as accurately and honestly as possible.

## **How did you decide what topics to study? Are these things known to cause birth defects?**

We do not know what causes or does not cause most birth defects. The purpose of the study is to find this out. Many topics were chosen because parents frequently have questions about them.

# Contact Information

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We hope you will participate in our study. The information you can give us is crucial. We believe this type of study holds the best promise for solving the mystery of birth defects.

## **For more information, please contact:**

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