

# Frequently Asked Questions About Biologic Sample Collection and Sharing Data

## What happens to the saliva samples?

Samples are labeled with a code number and stored until researchers are ready to use them.

## What kinds of tests will be done with my saliva samples?

We test the genetic material in your saliva sample for markers that might be associated with birth defects. In most cases, birth defects are caused by a combination of genes and other factors, such as exposures to certain medications or chemicals in the environment. Because of this, we will learn about the causes of birth defects by examining data from both telephone interviews and gene tests.

## Will I receive my results?

No, you will not receive individual test results. Instead, we will publish an e-newsletter that contains study results for large groups of families combined. This newsletter will be posted on our website [www.bdsteps.org](http://www.bdsteps.org). This newsletter will inform families of any major findings, especially if the results of a study might be useful for family members who are interested in genetic testing. Families can then talk with their doctor or genetic counselor to help them decide whether the gene test could be helpful to them.

## The consent form mentions putting my data in a centralized database. What does this mean?

This means that in the future your genetic and interview data may be combined with data from other children's health studies to do more research. Your names will not be included in the database. Only researchers and their institutions who have certified agreements to use the data for research consistent with the informed consent signed by study participants will be given access to the data. Researchers provided access will be required to use appropriate security measures.

## Can you explain about newborn blood spots?

Within the first few days after a baby is born, a few drops of blood are collected from an infant heel stick and dried on a card to test for rare conditions. After the tests are done, usually some of the spots on the card are left. If you live in a state that allows us to retrieve those spots, you may be asked for permission to share some of your child's blood spot. Just like the saliva samples, the blood spot samples will allow us to study genetic (inherited) factors that may contribute to the causes of birth defects.

## Why can't my results be sent to me?

The tests done on your samples are for research. This means that while our tests are done carefully, they do not meet the strict standards required for medical tests. Since these standards might not have been met, we will not send individual test results.

## Will a cold or illness affect the samples?

No, being sick won't affect the quality of the saliva samples. You can collect a sample even when a person is sick.

## Will collecting the samples hurt?

No, it will cause little to no discomfort for you or your family members.

## What if I collect the samples, and then forget to mail them for a while?

We will get better results if the samples get to us soon after they are collected. But the collection kits will protect the DNA and therefore you can still send them in later.

## What if everyone can't give samples or can't give samples at the same time?

It will be best if you collect all the samples at about the same time and then mail them. If you can't collect all the samples, please mail what you have. If you have other samples to send at a later time, you may call us and ask for another mailing envelope.

## What if I no longer want to be part of the study?

You may ask to be removed from the Birth Defects Study To Evaluate Pregnancy exposureS at any time. Please call 1-888-743-7324 if you want to be removed from the study. After receiving this request, we will destroy your saliva samples.

## Whom can I call if I have more questions?

You can call 1-888-743-7324, email at [BD-STEPS@abtassoc.com](mailto:BD-STEPS@abtassoc.com), or for more information about the study, please visit our website at [www.bdsteps.org](http://www.bdsteps.org)

Thank you again for participating in this important study of birth defects!