

# Frequently Asked Questions About Biologic Sample Collection and Sharing Data



## **Can you explain more about newborn bloodspots?**

Within the first few days after a baby is born, a few drops of blood are collected from the baby's heel and dried on a card to screen for rare conditions. After the tests are done, usually some of the spots on the card are left over. BD-STEPS would like your permission to get some of your child's leftover bloodspots. The bloodspot samples will allow us to study genetic (inherited) and other biologic factors that may contribute to the causes of birth defects. We will not collect any new bloodspots from your child.

## **Do you have information about the tests that were run on the newborn bloodspots at the state lab?**

No, we have no information about the results of the tests completed by the state lab. If any test results suggested your baby was at risk, you would have been contacted shortly after the tests were done.

## **What kinds of tests will be done in this study with my child's bloodspots?**

We will test genetic and other biologic material in your child's bloodspots for factors that might contribute to the causes of birth defects. Birth defects are probably caused by genes and other factors, such as medications or chemicals. We will learn about the complex causes of birth defects by examining data from both telephone interviews and genetic and biologic tests.

## **Will I receive results from my child's tests?**

No, you will not receive individual test results from BD-STEPS. Instead, we will publish an e-newsletter that reports study results without any names attached. This newsletter will be posted on our website [www.bdsteps.org](http://www.bdsteps.org). This newsletter will inform families of any major findings.

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

The tests done on your child's 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.

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

This means that in the future, some of your child's genetic and interview data may be combined with data from other children's health studies to do more research. Your child's name will not be included in the database. Only researchers who have permission to use the data for research will be given access to the data. Researchers will be required to use strong security measures.

## **Some BD-STEPS information mentions saliva (spit) samples. What does this mean?**

Just like the bloodspot samples, saliva samples will allow us to study genetic factors that may contribute to the causes of birth defects. However, having saliva samples from both child and parent will allow us to look at what genetic factors have been passed down from parent to child. In addition, saliva samples will give us better quality and more DNA. We hope that you and your family will collect saliva samples if we ask for them in the future.

## **Whom can I contact if my address or telephone number changes?**

It is important to let us know if your address or telephone number changes so that we can still invite you to be part of the saliva sample collection. You can call us at 1-888-743-7324 or email us at [questions@bdsteps.org](mailto:questions@bdsteps.org).

## **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 remove your interview information and your child's samples from all future study.

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

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

[Insert local contact sticker](#)

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