



national • birth • defects • prevention • study

How to Collect Cheek Cell Samples

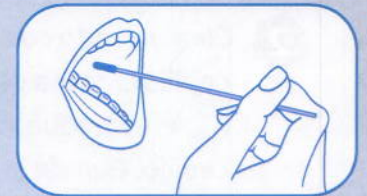
Thank you for agreeing to provide cheek cell samples. To collect the samples, we have included:

- Consent forms
- Cheek cell brushes inside colored envelopes (One colored envelope per person. Two brushes inside each colored envelope.)
- Postage-paid mailing envelope

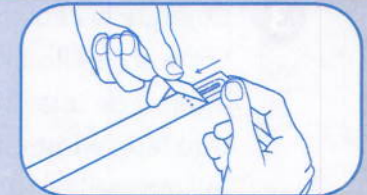
Please read the following directions before you start collecting the cheek cell samples. To watch a video of how to collect a cheek cell sample, please visit the website at www.nbdps.org

1 Read and sign the enclosed consent forms.

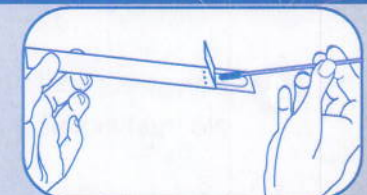
2 Starting with the red envelope labeled MOTHER, take out one cheek cell brush wrapper. Peel the white part of the wrapper down to where you see 3 stars (☆☆☆). Take the brush out of the wrapper. Be sure **NOT** to touch the brush end. Keep the wrapper; you will need it in step 4.



3 Place the brush inside your mouth, against the inside of your cheek. Rub the brush **firmly** up and down along the inside of your cheek **10 times**. Roll the brush on its other side and rub **firmly** up and down **10 more times** in the same area inside your cheek.



4 Put the brush back into the wrapper with the brush end first. Do not re-use this brush on another person.



5 Take out the second wrapper from the envelope labeled MOTHER. Repeat steps 2-4 with the second wrapper and brush. This time, use the brush on your other cheek.

6 Once you have put the brush back into its wrapper, put both wrappers back into the red envelope labeled MOTHER. Close the envelope with the clear seal. Write the **date** the samples were collected on the envelope.

7 After collecting your cheek cell samples, follow steps 2-6 to collect cheek cell samples from the other identified family members.

8 Place all colored envelopes and **signed** consent forms into the big, postage-paid mailing envelope. Securely seal the envelope and return it to us by U.S. mail **as soon as possible**.

If you have any questions or problems, please call 404-498-4315 or email ga@nbdps.org. Thank you!

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention



Frequently Asked Questions About Cheek Cell Brushes

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What happens to the cheek cell brushes?

Your brushes are sent to a central lab where the genetic material is removed from the brushes and checked for usability. Samples are then labeled with a code number and stored until researchers are ready to use them. Most samples are okay, but sometimes the lab may find out there is not enough material to study. In these rare cases we may ask for a second sample of your cheek cells.

What kinds of tests will be done?

The goal of our study is to understand the causes of birth defects. Some genes are already thought to be important in the causes of birth defects. We study these genes to learn how changes in them could lead to a birth defect. Other genes that have not yet been looked at in birth defects studies will also be tested. Many of the gene studies will need large numbers of families. Often, genetic material will be stored for many years before we have enough families for studies to be done.

Will I receive my results?

No, you will not receive individual test results. Instead, we will send a newsletter that contains important study results to all who participate. 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.

Why can't my results be sent to me?

There are several reasons why your test results are not sent to you. First, the tests done on your samples are for research. This means our study will look for connections between birth defects and genes. Before these connections can be useful, the tests need to be repeated in other labs using samples from other families. Until this is done, we cannot be sure these connections mean anything to individual families.

Second, in most cases, birth defects are caused by a combination of genes and other factors, such as exposures to certain medicines 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. In most cases, the results from one gene test will not be meaningful without knowing other information.

Third, 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 cheek cell 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, then forget to mail them for a while?

We will get better results if the samples get to us soon after they are collected. If your samples do not get mailed within a week, you can ask for another kit to collect new samples.

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

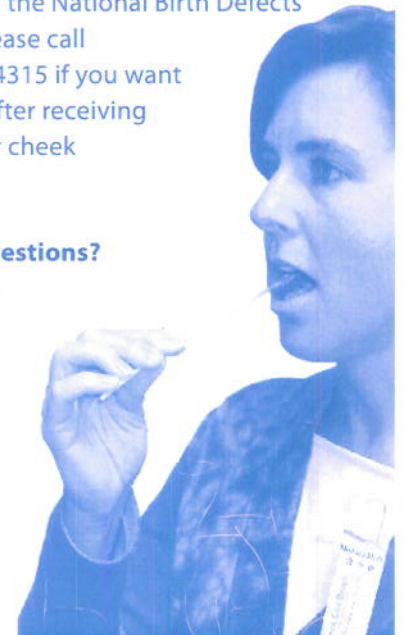
It will be best if you collect all the samples at about the same time and then mail them. But if this is not possible, you can mail what you have. If you have other samples to send at a later time, you may ask for another mailing envelope.

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

You may ask to be removed from the National Birth Defects Prevention Study at any time. Please call Tineka Yowe-Conley at 404-498-4315 if you want to be removed from the study. After receiving this request, we will destroy your cheek cell samples.

Who can I call if I have more questions?

You can call Tineka Yowe-Conley at 404-498-4315 or email ga@nbdps.org. For more information about the study, please visit our website at www.nbdps.org



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