

**Attachment 15G:
Buccal Cell Collection FAQs for North Carolina Respondents**

BUCCAL CELL COLLECTION FAQs

Do what?

- We would like for you to collect a sample of cheek cells. To do that, all you would do is rinse your mouth with mouthwash and return a sample to us. Everything you would need and the directions are provided. It's quick and easy to do.

Why participate?

- The buccal cell (cheek cell) collection is this study's most important contribution to science. There has never been a project of this magnitude for collecting genetic information that can help scientists understand why some people get cancer and other diseases and why others don't. This is really on the cutting edge of new discoveries in science. By completing the buccal cell sample, you are making a very important contribution to science, a contribution that will help us learn what we can do to promote good health for ourselves and our families.

Genes?

- We plan to study a wide range of genes that are important in how the body protects itself from tissue damage. These samples will be used to study genes that may play a part in why some people develop cancer and other diseases but others do not.

Consent form?

- The consent form has a lot more information than we give over the telephone. After you read it, you can decide how important it is. If you have questions and want to call us, a telephone number is included; however, we cannot use your sample without your signed consent.

Will this help?

- Knowing more about factors that promote good health can help everyone, especially in generations to come. You may not personally receive any direct benefits, but your participation will help with research that may uncover causes of diseases and risks.

Individual results?

- Usually in studies such as these, the individual results are not very meaningful, and for that reason study results cannot be given back to each individual. It is only when we look at groups of people, such as farmers as a whole, that we can get a good picture of what common genetic characteristics are important in predicting who might be at a greater risk of disease. We will let you know the overall results through newsletters and other publications.

Confidentiality?

The collection bottle for the buccal cell sample has a label that identifies participants through a barcode. For the protection of participants, names are not given. Your name and address will be separated from the data you provide. You cannot be named in any reports. If more than one individual in the household is asked to provide a sample, the two bottles will be labeled as “his” or “hers” to prevent confusion. In the Agricultural Health Study, personal information is never presented with a name.

Why farmers?

- Medical research suggests that while agricultural workers may be healthier, they may experience higher rates of leukemia, myeloma, non-Hodgkin’s lymphoma, and other cancers than people in more urban areas. Also, chronic diseases like asthma, neurological and kidney disease may be related to agricultural exposures.

Why AHS?

- This study is different from other studies because it focuses on health, not just your health, but on the health of your family. The primary goal of the Agricultural Health Study is to investigate the effects of environmental, occupational, and dietary factors on health.

Cloning?

- These cells will never be used for cloning. In fact, government-funded studies prohibit cloning experiments.

RESPONSES TO COMMON OBJECTIONS

No longer farming /Retired

- We especially need to include you because you no longer farm. The scientists will learn more about long-term effects of past exposures by studying individuals who are retired or who no longer farm. Occupational experiences and health conditions over a long period of time, and not just for the present time, are of interest. Your participation is very valuable.

Too sick

- I'm so sorry to learn about your illness. We wouldn't ask you for the buccal cell (cheek cell) sample if it weren't so important. It is important that the scientists be able to study the cells from individuals who are ill as well as those who are not, to evaluate individual differences. By comparing individuals who are diseased with those who are disease free, more can be learned about the role genes play in protecting us from diseases. If you feel up to doing this or if others help you, your sample would be very valuable. If others help, we would ask that only you handle the collection bottle.

Never farmed

- For buccal cell samples to be more representative, we need to include study participants with different work and health histories. We need everyone to participate. In addition, there are many factors that are of interest to the study such as diet and family health.

No time

- The buccal cell (cheek cell) collection is simple, easy, and important. It takes 5 minutes or less and is very important to science and to the study. You simply swish, spit, sign the consent form, and mail. We will send you all the supplies needed, including a pre-addressed and stamped envelope to return the sample.

Can't use mouthwash

- You can spit directly into the container and then fill the container to the red line with the mouthwash. That way you will not have to swish with mouthwash, but the cells in the saliva will be preserved. The buccal cell collection is very important to the study, and we would very much appreciate your participation.

Look it over

- We would be glad to mail a kit to you. We will enclose \$5 in the kit to provide for any inconvenience. You can then decide whether to take part after you receive the kit.

I already did that. Did you get my sample?

- Let me check our records:

IF YES: Yes, I see here that we received your buccal cell sample in Phase 2, several years ago. Thank you! Since scientists are interested in changes in genetic structure that occur over a period of time, another sample *now* will be even more valuable to the study (as a comparison). We will send you a packet with everything provided. As you may recall, it just takes a few minutes to do the mouthwash rinse, sign the consent, and return the sample in the mail. We would appreciate your help for this important part of the study. May we send you a kit?

IF NO: Our records do not indicate that we have a buccal cell sample from you. (It may have been lost in the mail, or at the lab, or there may have not been enough liquid in the container when it was received at the lab.) Again, this is the most important part of the study for understanding how genetic factors influence health, so we would like to send you another kit. It just takes a few minutes to do the mouthwash rinse, sign the consent, and return the sample in the mail. We would appreciate your help for this important part of the study. May we send you a kit?