

**Attachment 15D:
Buccal Cell Answers to Questions for Iowa Respondents with NHL**

**AHS: BUCCAL CELL COLLECTION
ANSWERS TO QUESTIONS**

- ***What are you going to test for?*** We are looking for genes that may help us identify groups of people that may be at a higher risk of developing non-Hodgkin lymphoma, while others exposed to the same toxins don't. We'll be combining this genetic information with information from questionnaires about exposures. Then we'll try to determine what genetic and exposure patterns are associated with non-Hodgkin lymphoma.
- ***What about cloning—what could be done with these cells?*** These cells will not be used for cloning; they can only be used for this study. Government-funded studies prohibit cloning experiments.
- ***I would like the test results.*** To protect the confidentiality of your sample, we immediately disassociate your name and other identifying information from the sample and store it by ID number only. That would make it very difficult to get back to you with results. Also, with the little that is known about genetic markers at this point, your individual results would be meaningless anyway. They simply don't know what is normal or abnormal yet and don't know which genes contribute to most diseases yet. The purpose of collecting the samples is to try to learn more about these things.
- ***I would like to be informed as to what tests are going to be performed on the cells and when they are testing.*** We will keep you informed through newsletters and other publications on the types of analyses we are doing as a whole, and will let you know the overall results for the study.
- ***What do you mean by environmental exposures?*** This refers to all of the different things your body comes into contact with, particularly as the result of where you live and your occupation. It includes chemicals, such as pesticides, as well as sunlight, grain dust, and other elements in your environment.
- ***What do you mean by other body processes?*** We mean for example, how the body defends itself against infection, how the nervous system is affected and any effects on the reproductive system.
- ***I do not want to sign a release form or anything else, but I will send you the sample.*** We cannot use any material you send us unless you consent to its use. We appreciate the fact that you are willing to participate, and would ask you to reconsider signing the consent form. You are free to

withdraw your consent at any time by simply notifying us that you wish to withdraw from the study and have your materials removed.

- ***Why do you need these samples, can't you draw blood instead?*** Collecting cells this way is easier on our study participants. Many people do not like to give blood, and we can get good information for our purposes from the cheek cells if the instructions are followed carefully.
- ***What do I have to gain by this if I can't receive any results?*** Although you personally may not receive any direct benefits, your participation is helping all farmers and their families, by helping us with research that may uncover the causes of disease that farmers are more likely to have. This understanding of farmers' risks may also help us understand the risks to the general population.
- ***Okay to collect the sample when I have a cold or other illness?*** Yes, this should not affect the sample.
- ***Okay to collect the sample when I'm taking antibiotics or other medicines?*** Yes
- ***Can I substitute my own mouthwash, rather than use the Scope we send me?.*** We prefer that they use a mouthwash with alcohol in it to better preserve the sample, but we will accept the sample with any mouthwash of their choosing.
- ***If you send it to me now, I may not get to it for a while. Is that okay?*** Yes. It helps us if you can complete it and send it in soon, but if it does take awhile, that will be fine too.
- ***I'm in the middle of [planting, harvest].*** We know you are very busy right now, but if you put the kit right next to the sink where you brush your teeth in the morning, it will be right there and will take only a few minutes of your time. If at all possible, please do it as soon as you can. We would greatly appreciate it.