

## Working Toward Wellness Youth Assent Form for Physiological Data Collection

Today we want to talk to you about what it's like to be a young person these days. Your mother said it is OK for me to talk with you today, as long as it is OK with you.

### **Learning about stress**

In addition to asking you some questions, we are also interested in learning from you how your daily life affects how stressed out you may feel. One way for us to learn about this is to ask you questions, but another way is to measure something your body produces called cortisol. Cortisol is released into your body when you experience stress, and it also is produced at other times of the day as well. Cortisol can be measured in your saliva or spit.

In order to learn more about this, we would like to collect your saliva simply by having you spit through a straw into a tube. We will show you how to do this. It will only take a few minutes for us to do this. The purpose of collecting your spit is *only* to measure the levels of cortisol in your body. We will not be measuring anything else in your spit.

A separate number will be created for your spit sample and this information will be kept separate from your name, address, and other information that might identify you. Your name will not be on any of the samples, so even the lab getting the information from your sample for us will not have your name. We will destroy your sample as soon as the cortisol information from it is collected and checked for errors. The sample will only be used for this study and related research.

### **Learning about genes and the environment**

In addition, we are interested in understanding more about your genes, and their link between your genes and how you are doing and feeling. Genes are the characteristics that you inherit that make you who you are. Your hair color and eye color, for example, are determined by your genes. It turns out that some people's genes make them more sensitive to their environments than others, and we want to learn more about this. For this reason, we'd like to collect a sample of your genetic material, or DNA, from you. The procedure is very simple: we would only need you to spit into a small container to collect this information from you. It only takes a few minutes.

We would *only* look at things in your DNA that are related to how sensitive you might be to your environment and nothing else. We would not be measuring anything drug-related in the samples. And, as with the cortisol samples collected, each DNA sample will be marked with an identification number that will be kept separate from your name, address, and other information that might identify you. These samples will be destroyed as soon as the data is collected and checked for errors. The sample will only be used for this study and related research.

### **Collecting additional samples**

Finally, we are interested in seeing what your levels of cortisol are over the course of two full days. To do this, we will leave you with a home kit for collecting saliva samples to conduct yourself. We will also ask you to complete a brief daily diary asking you questions about your day. This will be completed once per follow-up day. Your parent will be asked to mail the samples to us and once we receive them, we will send a \$10 gift card. These samples will also be treated like the others we collect on the day we are with

you—they will be marked with an identification number and destroyed once they are checked for errors. The samples will only be used for this study and related research.

### **Summary of data collection**

In summary, we are seeking your permission to collect the following information:

- two saliva samples that we would collect from you now, one to assess cortisol level, and one to assess several genetic biomarkers
- three saliva samples collected on two follow-up days for a total of 6 additional saliva samples to assess your cortisol levels. These samples we will ask you to mail back to us.
- one daily diary on each of two follow-up days, for a total of 2 diaries. These diaries you will mail to us with the 6 samples.

### **Protecting your information**

It is important that you understand that participation in all of these activities are completely voluntary. You can choose to participate in the saliva collection, the DNA collection, or both. There are no known risks to collecting these samples.

We will do everything we can to keep others from learning about your participation in the research. We have a Confidentiality Certificate from the U.S. government that adds special protection for the research information that identifies you. It says we do not have to identify you, even under a court order or subpoena. You should know, however, that we may tell someone if harm to you, harm to others, or child abuse becomes a concern (this report would not be based on any information that comes out of any of your saliva samples). Also, the federal agency that pays for this study may see your information in an audit, but it too will protect your privacy. This Certificate does not mean the government approves or disapproves of our project.

### **If you have questions, ask us!**

You can ask any questions that you have about this portion of the study. If you have a question later that you didn't think of now, you can ask us later. Signing here means that you have read this paper or someone read it to you and that you are willing to do this part of the study. If you don't want to be in this part of the study, check the 'no' boxes. Remember, being in this study is up to you, and no one will be mad at you if you don't participate, or even if you change your mind later.

When I sign my name here, I am saying that I agree to have the following samples taken. I am also saying that I understand what I am supposed to do and that I may stop participating at any time.

#### Saliva collection to measure stress:

CHECK ONE:       YES                       NO

#### Saliva collection of DNA to understand how sensitive you are to the environment:

CHECK ONE:       YES                       NO

Additionally, I agree to have my saliva samples be used in future related research studies as long as my identifying (i.e. name, address, etc) information is not linked to my saliva samples:

CHECK ONE:       YES                       NO

Print your name \_\_\_\_\_

Sign your name \_\_\_\_\_ Date \_\_\_\_\_

Signature of Interviewer \_\_\_\_\_ Date \_\_\_\_\_