

ASSENT FORM

North American Wilms Tumor Study (NAWTS) AEPI10N4 Molecular and Genomic Epidemiology of Wilms Tumor

**Rayjean J. Hung, Ph.D., M.S. – Principal Investigator
Mount Sinai Hospital
Dalla Lana School of Public Health, University of Toronto
Hospital of Sick Children**

About the study

We would like to know if you would participate in a research study. The purpose of the study is to understand why young people get Wilms tumor. This project is being done by Dr. Rayjean J. Hung at the Mount Sinai Hospital and the University of Toronto.

If you participate, we will ask for two things: 1) we would collect a tumor sample and 2) we would collect left over DNA from your tumor or blood sample, both obtained from your hospital. We would get saliva samples from your parents and ask each of them to fill out a survey. One of them will also fill out a survey about you.

This research will not help you or your family, but it might help us understand why young people get Wilms tumor. Because we don't know what this research might mean for you, we will not give the results of your individual DNA tests to you or your doctor. We will be happy to give you the results of the whole study when it's over.

DNA: Description, collection, storage, and future use

DNA -- what is it? DNA is the genetic material in a person's cells that makes them unique. There are thousands of genes in each cell which are made up of DNA. By studying DNA, scientists can discover what genes might cause young people to get tumors.

DNA -- collection: We would collect a DNA sample from your blood taken as part of the Renal Tumor Biology and Biobanking Study.

DNA -- storage and future use: We will keep this DNA at our lab for a very long time in case there are things that we want to look at in the future that we haven't thought of yet. You can ask to have your DNA sample destroyed if you want to until 2018. After that we will not have your name and won't be able to tell which DNA sample is yours. If you turn 18 before 2018 we will contact you to ask if we may continue to keep your DNA sample at our lab.

Making your choice

Whether or not you participate in this study is totally up to you. If you have questions right now you can call us at 1-416-586-4800 ext8134. Or, if you have questions later that you didn't think of now, you can call us or have one of your parents call us and talk to Dr. Rayjean J. Hung. Her phone number is 1-416-586-4800 ext8134. If your phone carrier/plan does not have long-

distance calling option, you can reach Dr. Hung and her associates at the study toll-free number 1-855-586-8815.

If you are hurt as a result of participating in this research, please call us or have your parents call us right away so that treatment can be provided.

Signing here means that you have read this paper, or someone has read it to you, and that you are willing to let us collect your left over DNA and tumor sample. **If you don't want to do these things, don't sign.** Remember, this is totally up to you. No one will hold it against you if don't sign this, or even if you change your mind later.

Signature of Child

Date

Signature of Parent Obtaining Assent

Date