

## Survey for NWTS Participants and Co-Twins

The survey you are about to complete is part of a series of studies designed to uncover the extent to which Wilms Tumor is inherited. In this study, we are assessing whether or not the co-twins of NWTS participants with Wilms Tumor have an increased likelihood of developing Wilms Tumor. This is a follow-up study to a similar one that we undertook in 1993. The results of the 1993 study were reassuring to families because, in the majority of cases, it does not appear that Wilms Tumor development is due to genetic influences. Now that there are more twins registered with our study, we would like to update these results. This brief survey will take 5-10 minutes to complete and is completely voluntary. If you have any questions about the survey, the NWTS or Wilms Tumor in general, please call 1-800-553-4878 and we would be happy to answer them. If you would prefer to return the questionnaire by mail, please email us at [nwtsg@fhcrc.org](mailto:nwtsg@fhcrc.org) and we will send you a business reply envelope to return the completed survey form.

Your Name (include maiden name): \_\_\_\_\_

Sex:    M        F

Has anybody else in your family had Wilms Tumor?

Yes         No

### **If Yes:**

There is a rare variant of Wilms Tumor called "Familial Wilms Tumor." It is important for us to document such reports in order to better understand the genetics of this condition. May we send you a packet to forward to this relative? The packet contains a request for their approval for us to contact them and find out more about their diagnosis.

Yes         No

*(If twins are of the same gender):*

Are you and your twin identical?        Yes

No

How was this determined? \_\_\_\_\_

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Are you alike as two peas in a pod?        Yes

No

*If No: Were you before you or your twin's treatment for Wilms Tumor?*

Yes  No

First I would like to ask some questions about your health history.

Have you ever been diagnosed as having any of the following syndromes?

**Beckwith-Wiedemann syndrome?**

(This syndrome is characterized by a large tongue, low blood sugar at birth, and a malformed belly button or wall of the belly.)

Yes  No

**Denys-Drash Syndrome?**

(This syndrome is characterized by kidney failure that an individual is born with.)

Yes  No

**WAGR Syndrome?**

(Called Wilms Tumor, Aniridia, Genitourinary Abnormalities, and Mental Retardation Syndrome. It is a genetic condition and typically two or more of these above mentioned defects are present in an individual with WAGR.)

Yes  No

*(Please complete the next question for FEMALES only)*

**Turner Syndrome?**

(This can be characterized by shortness of stature, a wide neck, abnormal ovaries, and the presence of only one X chromosome.)

Yes  No

Do/did you have any of the following conditions present at birth?

**Hemihypertrophy?**

(This is when one side of any part of the body is noticeably larger than the other side.)

Yes  No

**Aniridia?**

(This is when an individual is born without the Iris in the eye.)

Yes  No

**Congenital Heart Defect?**

(This a problem with the heart that an individual is born with.)

Yes  No

*(Please complete the next two questions for MALES only)*

**Cryptorchism?**

(This is undescended testicles.)

Yes  No

**Hypospadias?**

(This is when the urethral opening (the location where urine exits the body) is in an unusual place.)

Yes  No

**Other Defects of the Urinary or Genital Systems?**

Yes  (please describe) \_\_\_\_\_  
\_\_\_\_\_

No

**Other Congenital Conditions?**

Yes  (please describe) \_\_\_\_\_  
\_\_\_\_\_

No

If you aren't the NWTs participant, please tell us if you have ever had Wilms Tumor?

Yes  No

**If No (skip to “A”)**

**If Yes:**

When were you diagnosed? \_\_\_\_\_

Where were you treated (hospital, city, state)? \_\_\_\_\_

\_\_\_\_\_

Who was your Physician? \_\_\_\_\_

May we contact the institution to get more information?

Yes  No

**If Yes:**

We will need your signed permission in order to obtain this information. I will send you a consent packet in the next few days. Please sign the forms and return them in the pre-paid envelope provided.

**“A”**

Have you had any other kind of Cancer? Yes

No

**If No (skip to “B”)**

**If Yes:**

What kind? \_\_\_\_\_

Where were you treated (hospital, city, state)? \_\_\_\_\_

\_\_\_\_\_

When was it diagnosed? \_\_\_\_\_

Who was your Physician? \_\_\_\_\_

May we contact the institution to get more information?

Yes  No

**If Yes:**

We will need your signed permission in order to obtain this information. I will send you a consent packet in the next few days. Please sign the forms and return them in the pre-paid envelope provided.

**“B”**

Thank you for taking the time to talk with me today and for helping us with this part of our study. We appreciate your family’s participation in the study over the past years.

Please feel free to send us any questions that you think of by mail, email, through our website, or by calling.

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Thanks again.