

## Survey for Parents

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.

NWTS Participant Name (include maiden name): \_\_\_\_\_

Co-twin Name (include maiden name): \_\_\_\_\_

Your Name: \_\_\_\_\_

NWTS Participant Sex:    M    F

Co-twin 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 the twins are of the same gender):*

Are the twins identical?            Yes

  No

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

Are they alike as two peas in a pod?      Yes   
No

*If No: Were they before your child's treatment?*

Yes       No

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

Has she/he had any kind of cancer other than Wilms Tumor?      Yes   
No

**If No (skip to section "A")**

**If Yes:**

What part of the body? \_\_\_\_\_

Where was he/she treated (hospital, city, state)? \_\_\_\_\_

\_\_\_\_\_

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

Who was his/her 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"**

Has the participant or their twin 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.)

Participant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Twin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

**Denys-Drash Syndrome?**

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

Participant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Twin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

**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.)

Participant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Twin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

*(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)

Participant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Twin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

Does/did the participant or their twin 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.)

Participant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Twin	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

**Aniridia?**

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

Participant Yes  No

Twin Yes  No

**Congenital Heart Defect?**

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

Participant Yes  No

Twin Yes  No

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

**Cryptorchism?**

(This is undescended testicles.)

Participant Yes  No

Twin Yes  No

**Hypospadias?**

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

Participant Yes  No

Twin Yes  No

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

Participant

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

No

Twin

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

No

**Other Congenital Conditions?**

Participant

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

No

Twin

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

No

Has their twin ever had Wilms Tumor?

Yes

No

**If No (skip to "B")**

**If Yes:**

When was he/she diagnosed? \_\_\_\_\_

Where was he/she treated (hospital, city, state)? \_\_\_\_\_

Who was his/her 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”**

Has their twin had any other kind of Cancer?

Yes

No

**If No (skip to “C”)**

**If Yes:**

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

Where was he/she treated (hospital, city, state)? \_\_\_\_\_

\_\_\_\_\_

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

Who was his/her 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.

**“C”**

Thank you for taking the time to complete this survey and for helping us with this part of our study. We hope you will continue with your participation in long-term follow-up of Wilms Tumor patients. 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.