Who Is Eligible for the Late Effects Study?

We have been asked by a number of Wilms tumor survivors who were not registered on our study at the time of diagnosis if they can be enrolled on or contribute information to our Late Effects Study. We appreciate the generosity of these offers and recognize that they are made with the motivation to share information that may lead to improved treatment and long-term outcome. Regretfully we cannot accept these offers.

The NWTS Late Effects Study is funded by the National Cancer Institute (NCI) and subject to their regulations. There are a number of elements that make someone eligible to participate in the NWTS Late Effects Study.

- First, you must have been specifically **consented** to be treated on one of our five clinical trials. Informed consent is mandatory to be on our protocol studies, and without it candidates are immediately ineligible.
- Then you must have been **registered** on one of our clinical trials. All clinical trial data should have been submitted to the NWTS on forms designed by the NWTS for institutions to collect consistent data unique to the NWTS. If treatment was outside of a participating institution, the physician would not have access to these NWTS forms and could not provide the NWTS with complete data.
- Tissue from the tumor should have been sent to the NWTS Pathology Center for Central Pathology Review. This review by the NWTS Pathologist results in yet more data specific to the NWTS. The **reviewed diagnosis** must have been Wilms tumor, Clear Cell Sarcoma of the Kidney, or Rhabdoid Tumor of the Kidney.

The above is the summary picture of eligibility. Our clinical trial protocols must adhere to very strict guidelines in order to provide scientifically valid results. While we very much value offers to provide us data about Wilms tumor experiences from people not registered on the NWTS, we cannot currently include these in analyses because we are prohibited from using them in any way. Even in our newsletter, our information must be based upon eligible patient data. According to the rules that govern how we communicate about late effects, we cannot use anecdotal data.

However, if you were diagnosed with Wilms tumor after September of 1969, you might have been enrolled on one of our clinical trials and now be eligible for the Late Effects Study. If you would like to find out, please **contact us**.