

Following Participants' Children

“Will My Diagnosis and Treatment of Wilms Tumor Affect My Children?”

We have no reason to believe that your children are at increased risk for any health problems, but we cannot make an authoritative statement about this until we have enough documentation. Therefore this is a question we are also currently researching. We are asking parents to permit us to follow their children's health each year. We will periodically assess the information to see if there are any trends developing.

We know it takes time to complete and return our forms, and we do not want to impose a new burdensome layer of questions to what we already ask. When you receive the form regarding your children we believe you will find it very brief and easy to complete. If you do not find this to be true, please let us know. Thanks in advance for helping with this important aspect of the study.

Adult Consents: A Question from a Participant

We received this question: *My parents consented for me to participate in the study when I was diagnosed. Why are you asking me to sign another consent?*

If you were under 18 when you were diagnosed, your parents signed a consent form as your guardians. Once you have reached your eighteenth birthday, you are legally an adult. As an adult you now are responsible for what information you share with us. We can receive your consent either verbally or in writing.

While we want your continued participation in the study, the consent form also gives you the opportunity to decline participation. Whatever you decide to do, we would appreciate receiving your decision verbally, via email or in writing.

Some young adults are busy with college or new careers and prefer that we continue to contact their parents. We certainly understand this, and can do this if we have your permission. If this is your preference, please let us know, and we will continue to contact your parents until you tell us to begin contacting you directly.

National Wilms Tumor Study

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