



Your Participation in the Study Benefits Thousands

In March of 2006 we submitted an application to the National Institutes of Health for approval to be funded for another five years. Every five years we have to compete with many other researchers for continued funding. Currently fewer than 10% of applications are approved, clearly a very competitive process. In July we learned that our application was approved. Reviewers noted "This application is considered highly significant as the long term effects of Wilms tumor therapy are important not only for survivors of Wilms tumor, but also to survivors of other pediatric cancers."

Our application would not have been successful without each of you returning our forms, agreeing to our requests for additional information, and enrolling your children on the study. Thank you. We want to share the reviewer's comment to let you know that thousands of survivors of other childhood cancers have benefited from your contribution to the study. Chemotherapy and radiation therapy (RT) used to treat Wilms tumors are also used to treat other childhood cancers. Over the years the NWTS has pioneered changes in how RT and chemotherapy are given which has reduced toxicities and duration of treatment. Other children benefited from these treatment changes and have you and your families to thank for the improvements.

We thought you would like to know that you have made significant contributions to the lives of many, many people besides your fellow Wilms tumor survivors. You have our heartfelt thanks and congratulations.



Why We Need to Hear Your Good News

by Norman Breslow, Ph.D.

As the statistician and Principal Investigator for the NWTS Late Effects Study, I sometimes receive e-mail from former Wilms tumor patients who have just been diagnosed with a second tumor or who have had a complicated pregnancy. I refer such correspondence to NWTS staff members who will contact the person to obtain further details. What many former patients fail to recognize, however, is the importance of hearing also from the great majority of you who have not experienced problems with your health. This is so that we may report to you, and to the physicians who treated you via articles in the medical literature, accurate information on rates of occurrence of second tumors, low birth weights and other factors that we track. Such rates consist of both a numerator and a denominator. The numerator is the number of cases (e.g. of a second tumor or a low birth weight baby) that occur before a certain age. The denominator is the much larger total number of former patients who have been followed through that same age. We can only include you in the denominator if we receive news from you regarding your health status. If we hear more frequently from patients in the numerator, we overestimate the rate and make it appear that the medical conditions following diagnosis and treatment of Wilms tumor are worse than they really are. This is sometimes known as the principle that "bad news travels fast." It can lead physicians to make treatment decisions for their current patients based on wrong information.

So I urge all of you to keep in touch with us on a regular, annual basis. While of course we need you to report any adverse medical condition, we also want to hear your good news—of graduation, employment, marriage, pregnancy or just the fact that you are still at your present address and receiving our newsletters. I hope to hear from all of you soon.