

FAQs Continued

How long will you follow me/my child?

We plan to follow you/your child once a year throughout your lifetime through correspondence directly with you/your child or your physician or the institution where you/your child was treated.

What about confidentiality?

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality, but only those involved in the science of the study will be granted access to your medical records or any other person information. Your personal identity will not be revealed in any publication or report.

What does the LATE study involve?

Participation involves completing a brief Annual Status Report form every year that asks about significant health events and confirms that we have your most recent address on file. Every five years we send a more detailed Medical History Form for you to fill out and a Physical Exam Form for your physician to complete and return. Reports of conditions of particular interests are followed up with requests for consent to obtain confirming medical records. Currently conditions of interest include pregnancy in participant or partner; heart, kidney, or lung conditions; the development of other cancers; and the diagnosis of Wilms tumor in a family member.

What are the risks of participation in the study?

We respect that each person has a different comfort level with sharing certain aspects of his or her medical history, and this discomfort is the primary risk of participation. However, we ask that you let us know if there is a particular part of the study for which you would rather not provide

continued p. 4



For more answers to FAQs see <http://www.nwtsg.org>.

Cure Rates Over Time

When discussing this topic once before a lay audience, I emphasized how far we had come in such a short time.

A member of the audience then said “I don’t think that is so good; it has taken you 70 years.”

That is correct, but we need to see this in another context. The time frame becomes clearer if we take all of human history and put it on a 24-hour clock. Having done so, we see it is now one minute after midnight, and all children with Wilms tumor will die. It is 3 AM and none survive. It is 6 PM, 9:00, 10:00, 11:00, and all children with Wilms tumor die. It is 11:15, 11:30, 11:44, all succumb.

It is 60 seconds later, and 5% live. It is 11:47 and 15% survive. Four minutes more, and 45% are alive. Another four minutes and 80% are cured. It is 11:59. Ninety percent of the children will live, most to become healthy adults: and the clock is still ticking for us—and for them.

Giulio D’Angio, MD,
Founding Chairman of the NWTSG

Know Your Diagnosis and Treatment

In this excerpt, “Cure Is Not Enough”, interviewer Bonnie Allen talks with Wendy Hobbie and Kathy Ruccione, co-authors with Nancy Keene of **Childhood Cancer Survivors: A Practical Guide to Your Future** (copyright 2000 by O’Reilly & Associates, Inc.) about important survivor issues such as the importance of knowing your/your child’s diagnosis and treatment.



Hobbie is coordinator of the FU Program at the Children’s Hospital of Pennsylvania (CHOP), and Ruccione at Children’s Hospital Los Angeles (CHLA), where she established the CHLA LIFE Program for survivors.

Ruccione: One of the things Wendy and I hope to accomplish with this book is for survivors to understand that potential late effects vary according to their disease and the specific treatment they received. Long-term survivors sometimes get hold of information about the range of possible late effects and assume it applies to them. In fact, it’s a very individual matter. This underscores how important it is for parents and survivors to keep records of their illness and treatment.

Allen: What are some specific steps you’d advise a parent or survivor to take after treatment ends?

Ruccione: Number one, know what their diagnosis and treatment were, and learn what needs to be monitored in the future. They may want to schedule an ap-

pointment to talk with their treating physician, outside of the usual appointments for tests and physical exams. Sometimes it’s called an “exit interview,” but it’s not a real exit—we don’t really want them to disappear from our lives! We want to help them monitor their health into the future—to be knowledgeable about their own history so that they have that knowledge at hand if they go to another health care provider who may not know very much about childhood cancer.

Allen: In the back of your book is a tear-out health history pamphlet with space for survivors to record treatment information. Did you include that with the exit interview in mind?

Hobbie: Yes. All patients should have an exit interview. However, many institutions do not have exit interviews and families have found it difficult to get all the necessary information about treatment and potential late effects once treatment has ended.

The pamphlet can act as a guide to what information is important to gather. In a situation where an exit interview isn’t

continued next page