


Study of Cancer Risk in Other Family Members of Wilms Tumor Patients *(continued from page 1)*

suggests that extended families of Wilms tumor patients are not at a higher risk than other people for cancer. However, there were some subgroups that were difficult to evaluate because of their small numbers. These included the parents of former Wilms patients. They had more cancers than expected but because of the small numbers the difference is within the limits of chance fluctuations. Your continued participation in the

National Wilms Tumor Long Term Follow-up Study will allow us someday to better answer questions such as this.

If you would like to read the paper discussing this study, it is entitled "No Excess of Early Onset Cancer in Family Members of Wilms Tumor Patients" and was published in the September 15, 2001 issue of *Cancer*, Vol. 92, No. 6 and a summary is available on the NWTs web site: <http://www.nwtsg.org>. 

Please find below an article from our colleagues at the Minnesota Long Term Follow-Up Study (LTFU.) Some of you are participating in both our study and theirs, and we are pleased to have this opportunity to provide all our participants with information about them. We know that your time is extremely valuable and want you to understand why you might be asked to participate in more than one study. We want to emphasize that the studies cooperate to use as little of your time as possible.

Our study focuses exclusively on patients with Wilms tumor and includes all survivors of the National Wilms Tumor Study from North America who agree to participate in it. It uses the largest, most comprehensive cohort of patients ever assembled, over 8000 since 1969. The Minnesota Long Term Follow-Up Study includes patients from selected institutions in North America with all types of childhood cancer. It studies a much smaller number of patients with Wilms tumor.



Minnesota Long Term Follow-Up Study

By: Catherine Moen, LTFU Newsletter Editor

With current therapies, over 70% of children diagnosed with cancer and similar illnesses can be expected to become long-term survivors. The Long Term Follow-Up study was begun to address the needs of these individuals, many of whom have grown to adulthood and now face the likelihood of experiencing delayed effects from the treatment of their illness.

The LTFU is a study of children and adolescents who survived five years following the treatment for cancer or similar illnesses. Participants were diagnosed between 1970 and 1986 at one of 25 collaborating research centers. The National Cancer Institute has funded the LTFU study since it started in 1994. The study is coordinated by the University of Minnesota.

More than 14,000 survivors and about 3,500 siblings of survivors actively participate in the LTFU study. The siblings serve as the study's comparison group. (Of interest to readers of the NWTs newsletter, the study includes 1,213 participants who were diagnosed with kidney cancer.) Participants provide information to study researchers about their health and health-related behaviors through written and telephone

questionnaires. They are also asked to give permission for the study to obtain medical records of their diagnosis and treatment for their original illness. In addition, the LTFU study collects certain biologic specimens, which are used to study genetic factors of cancer treatment.

The mission of the LTFU is to investigate the long-term effects of treatment and to provide health-related education to its participants. Study investigators have reported on several important topics, including early and excess mortality among survivors, the occurrence of second cancers, and the psychological health of study participants. A recent paper reported on the finding that cancer survivors lack specific knowledge about their treatment for their illness. (This can make it hard for survivors to obtain appropriate follow-up medical care.) The study provides research updates and other health information to participants in a newsletter that is published twice a year. Additional information about the LTFU study, including copies of the newsletters and the study questionnaires, can be found at the following web site: www.cancer.umn.edu/ltfu. 