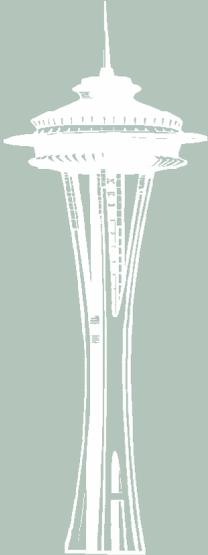


LATE BREAKING NEWS

FROM THE NATIONAL WILMS TUMOR STUDY

Volume 2, Winter 2003



Hello Again From Seattle

Hello again from Seattle and thank you. Many of you called or emailed us since you received our first newsletter, and we appreciate your comments and suggestions. This second newsletter has been designed to provide some advice, explain some of the mailings we send to you, and introduce you to two members of staff many of you have talked with on the phone. Sarah Christie has interviewed many of you regarding pregnancies. Bobbi Benson talked with several hundred participants and family members during an interview study funded by the American Cancer Society. These

“we appreciate your comments and suggestions”

important interviews resulted in an article described in the enclosed article by Dr. Judy Felgenhauer, the principal investigator for the project. The information you provide to us by mail or phone has and will result in important findings.

So, thank you for the contributions you make through your participation. The information you provide will help children diagnosed in the future with Wilms tumor to benefit from findings about improvements in treatment and long-term health. They will owe you immeasurable thanks, as do we. 



Study of Cancer Risk in Other Family Members of Wilms Tumor Patients

By: Judy Felgenhauer, MD, Pediatric Oncologist

Between 1995 and 1997, we interviewed 296 families to determine if members of the families of Wilms tumor patients have a greater than expected incidence of cancer before the age of 55. We appreciate the participation of many of you who were randomly selected to be contacted for this study and we also appreciate the participation of your relatives who willingly shared their medical histories and records with us to advance our knowledge of Wilms tumor.

We attempted to contact 530 patients (and their families) treated on National Wilms tumor studies (NWTs) between 1970 and 1992. We received permission to contact these families from their doctors at the hospitals where they were treated for Wilms tumor. We then sent letters to the families inviting them to participate in our study. Only 64 families either refused to participate or never responded to our attempts to contact them.

A telephone interview was conducted with the patient or most commonly, the patient's mother. We

requested information on the NWTs patient and the patient's parents, offspring, siblings, half-siblings, grandparents, aunts, and uncles. We asked about dates of birth and death, birth defects, and occurrence of any cancer prior to the age of 55 in each of these family members. If a cancer was reported, we asked to speak with that relative. A separate interview was then carried out with this person and, with their permission, the cancer was verified with medical records.

Using this approach we were able to verify there were 99 cancers in the 4,258 members of the 296 families we interviewed. Using information from a national cancer registry called Surveillance, Epidemiology and End Results (SEER), we could predict the number of cancers we should have seen in this population, based on the ages of all the relatives.

We evaluated the results for the whole group and then for specific subgroups. In the group as a whole we would have expected to find 127 cancers. Since we only found 99, there were fewer cancers than expected. This

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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. 