

LATE BREAKING NEWS

from the **National Wilms Tumor Study**



Commercial image, actual participant photos are not displayed

Our Photo Gallery

Have you been on a fun vacation? Had a new class photo taken? Gotten married? Had dinner with your family? Had a baby? Had a grandchild? Whatever you have recently done, if you had a photo taken, we would love to receive a copy. The picture represents our gallery of photos participants have sent us to share their experiences. We keep this posted as a constant reminder of what is most important to the study: your progress through life. We love to receive your photos. Although it may look like we are running out of room, we always have space for you. Please, keep the photos coming. ■

A Study Participant Recently Asked “What Good Results from My Reporting My Health Status to You?”

The answer is: A lot.

The information gathered in the Study documents the delayed complications encountered in some patients treated with the various drug and radiation therapy (RT) combinations that have been employed over the last 4 decades. Because of the information gathered, treatments have been modified to avoid some of these problems. For example, documentation of the growth problems that can follow RT has restricted RT to patients known to be at higher risk of relapse to the original tumor site. It has also led to reductions in the RT doses used. These dose reductions have not only minimized bone growth deformities but have also decreased (1) the chance of developing a second cancer in the irradiated area, and (2) have reduced the risk of damage to other organs like the liver, lung and heart that may have been included in the RT field.

The Study has also provided re-assurance to young couples starting their families. Data accumulated in the Study show there are no increased chances of identifiable congenital deformities in babies born of parents treated with the chemotherapy drugs and RT as it has been used in the NWTS. At the same time, experience gathered through these patients has alerted gynecologists, obstetricians, and the women themselves that those receiving even low-dose RT to the flank need expert pregnancy surveillance. This is because of the increased chances of delivery a few weeks earlier than expected. Similarly, girls treated with doxorubicin (Adriamycin) need supervision during pregnancy because of the added demands made on the heart, especially during labor.

National Wilms Tumor Study

Fred Hutchinson Cancer Research Center

1100 Fairview Avenue North M2-A876 PO Box 19024 Seattle, WA 98109

206.667.4842 800.553.4878 fax 206.667.6623

www.nwtsg.org nwtsg@fhcrc.org

The list could be lengthened, but the point is that this information has been made available widely through dozens of books and hundreds of published articles, frequent conferences here and abroad, and through the inclusion of relevant guidelines in national and international protocols.

In addition, the records of the study can be searched for other instances of specific, unusual problems that are sometimes reported by participants. Then, the staff in Seattle can enlist Study physicians for help and even provide contact information—with permission, of course—between the affected patients if they so wish.

Thus, adults treated 30 or 40 years ago can be watched more carefully and more specifically for the possible adverse secondary effects of the treatments given then. Equally important is the fact that children being treated today have had intensity of therapy cut back wherever possible to avoid those complications identified through data collected by the Study and others like it.

So, not only do more than 9 in 10 children with Wilms tumor now survive, but most survive into adulthood with far, far fewer scars—visible and invisible, physical and psychological—than those who went before. Participants who faithfully report data in the Study have played an important role in the striking progress that has been made. You should be proud. ■

BREASTFEEDING SURVEY II

Last year our newsletter ended with a short notice that we were sending out a new and improved breastfeeding survey in the near future. Those of you who were expecting to receive this have noticed that you did not receive a copy. That is because shortly before we did the mailing we found some serious deficiencies in the form. It has taken us awhile to properly revise this form, but we believe we now have a truly new and improved form to send. Participants should be receiving these soon.

An Update on Pregnancies

Have you or your partner reported a pregnancy to us? If so, we have asked you to complete a form and to give us permission to obtain copies of medical records. What in the world do we do with all this information? Those of you who received our 2002 Newsletter, read a reprint of a published interview with NWTS Study Chairman Dr. Daniel Green. Dr. Green reported results from our first publication (*Pregnancy Outcome After Treatment for Wilms Tumor: A Report From the National Wilms Tumor Study Group: Journal of Clinical Oncology 2002 May 15; 20(10) 2506-13.*) The findings resulted from the data we collected about pregnancies, births and newborns' health. In 2010 we will publish the follow-up to this report. The number of pregnancies has more than doubled since the earlier study. We will update what we know and provide physicians with even better information about how Wilms tumor survivors and their partners should be monitored during pregnancy and childbirth. As soon as this is published we will post a notice on our website. ■

How Does the NWTS Protect My Confidential Information?

A participant asked this question recently, and while responding we realized that the topic is an excellent subject for a newsletter article. We do appreciate your willingness to share confidential information with us, and want you to be assured that confidential information is secure. Please find below our response to the above question. If you have any concerns or questions left unanswered, please let us know.

The NWTS Data and Statistical Center (us) is located at the Fred Hutchinson Cancer Research Center (FHCRC) in Seattle. Following a rigorous review and site visit, the FHCRC Institutional Review Board (IRB) received accreditation by the Association for the Accreditation of Human Research Protection Programs. This is a national organization that ensures and confirms that this IRB meets the highest national level of standards and approval of all activities for which it is responsible (aahrpp.org). Every year the IRB conducts a complete review of all of our activities and procedures and renews its approval of our operation.

All NWTS staff are required to complete specialized training regarding the protection of confidential information, and we must renew this training every third year. The files in which we keep our paper documents are in offices in the Public Health Science department building on the FHCRC property. Beyond the first floor reception area only personnel with coded access cards can enter our work space. In addition, the rooms in which files are kept are accessible only with keys issued to staff working on our project.

When we analyze study data and ultimately publish findings, we report only statistical summaries and anonymous data. No one reading our reports can possibly identify individual participants. And finally, any paper records containing participant information are disposed of via shredding. We vigilantly guard and secure participant confidentiality; it is a duty and responsibility we take very seriously.

If you have any concerns or questions regarding the use and confidentiality of your information, please contact us. ■

Survey Monkey

Have you recently received an Annual Status Report (ASR) from us? Do you want to report new information? Perhaps you just want to let us know how you are doing? Anytime you would like to send any kind of report, you can do so quickly, conveniently, confidentially and electronically. Just click on the link to Survey Monkey on our website, www.nwtsg.org. Using this link you can complete the ASR at your convenience, after which we can download the completed form and update your records.

Soon we plan to have more forms posted online for your convenience. Forms requiring your signature to permit us to obtain copies of medical records must still be completed by hand, signed and mailed to us.

REPORT BY SURVEY MONKEY –
SAVE TREES

WHO CAN REPORT FOR ME?

Why can't my mother/father/aunt report for me? If you are eighteen years or older anyone can report for you—as long as you give us written permission for them to do so. A Signature Authorization form is posted on our website under the Participants, Families and Friends page. If you would like someone else to report for you, please either print, complete and mail us this form, or ask us to mail it to you with a business reply envelope.



Portrait of a Pioneer

Dr. Audrey E. Evans was a co-founder of the National Wilms Tumor Study. We are pleased to share this portrait of Dr. Evans. She was recently honored by The Children's Hospital of Philadelphia (CHOP) for her 60-year career devoted to the improvement in treatments for childhood cancer. Her idea of hospital patient-family housing led to the creation of the first Ronald McDonald House in Philadelphia. This portrait was recently hung in CHOP.

Staff in Seattle share CHOP's admiration for Dr. Evans. She has visited us many times to work on projects, attend meetings, and share her wisdom and insights. These visits are always highly anticipated and warmly remembered. Thank you and congratulations, Dr. Evans from us and on behalf of all the children and their families who have benefited from all you have done. ■

Meet NWTS Statistician and Founder Norman Breslow, PhD

by Giulio J. D'Angio, MD

Norman Breslow was part of the original planning committee of the National Wilms Tumor Study (NWTS) in 1968. In fact, he is the longest continuously serving Committee member, maintaining his NWTS post for the past 40 years through his independently funded NWTS Late Effects Study. Those of us who remember the early days of the study look back on the steady guidance and wise counsel Dr. Breslow provided from day one. It was he who was accorded sole veto power over study design or planning that did not meet his rigorous standards. The clinicians' ideas of what were scientifically and clinically important questions to address had to meet Dr. Breslow's criteria of valid study design, feasibility and probability of significant outcome. Withal, he was flexible and showed great imagination in adapting new statistical methods and techniques to the study results. All analyses were and are dependent on accurate and up-to-date data files. His very successful organization and staffing of the NWTS Data and Statistical Center was critically important in this regard. He immediately implemented—this was 40 years ago—a computerized data base system developed by a colleague that permitted detailed information to be retrieved for analysis. The efficiency and accuracy of those data files are manifest in the more than 250 NWTS articles, book chapters, commentaries and editorials that have been published. He is a co-author of nearly all NWTS papers reporting new findings.



Not only did they pass under his alert eyes before being submitted for publication, but also he has always been intimately involved from the beginning in the formatting and analyses of NWTS reports. There is no doubt that the strength he and the DSC represented were critical factors in securing continuous funding by the NWTS over the years of its existence.

One of the ancillary benefits of his association with the NWTS is the fact they both grew up together, as it were. Dr. Breslow, in his academic role at the university, has been able to use those anonymous data files for teaching purposes. He has also presented for classroom discussion and class work some of the design and interpretation problems encountered by the NWTS during its several decades of life. Of course, Dr. Breslow's interests and activities range well beyond the confines of the NWTS. He has pioneered in the development of biostatistical and epidemiological methods and techniques as well as being co-author of two influential research monographs. These and his many other contributions to science have led to his international recognition as a leader in Biostatistics.

His career began its upward climb 40 years ago as a Fellow in the Department of Preventive Medicine at the University of Washington. It culminated when he was made a professor there in 1976 and the Chairman of the Department of Biostatistics from 1983-1993. Before that, he had served on two occasions as statistician to the International Agency for Research on Cancer, a part of the World Health Organization in Lyon, France. He and his wife, Gayle, very much enjoyed the years they lived in France. Many national and international honors have accumulated during the intervening years. The recipient of Honorary Doctorates from universities in France and Belgium, he is a member of the Institute of Medicine of the U.S. National Academies, an Honorary Fellow of the Royal Statistical Society of the United Kingdom, and an Honorary Life Member of the International Biometric Society for which he served as President in 2002-2003.

Dr. Breslow is tall and trim. He is an outdoors person, who enjoys Nature in all her manifestations. Perhaps he likes skiing and trekking across mountainous country most of all. The Cascade Mountain Range near Seattle has been the site of many joyous camping trips with his family and ski tours with friends, but he has gone farther afield as well. For example, he has explored the Himalayas in both Tibet and Nepal.

A major celebration of his notable career took place in Seattle in 2006. A symposium was convened in his honor and entitled, "Conference on Statistical Methods in Epidemiology and Observational Studies." From all over the world, many of his former students as well as other luminaries in the field attended the event, when the "Norman Breslow Endowed Lectureship" series was inaugurated. His role in the success of the NWTS was reviewed at that time. The two-year survival rate for children with Wilms tumor, in percents, has climbed from the low 80s when the first child was enrolled in the NWTS in 1969, to the high 90s today. Not only that, but treatment intensity and duration have been reduced. Thus, more children will survive with fewer long term disabilities—lucky them and lucky us for having had Dr. Breslow with us during these productive decades. ■

RECENT PUBLICATIONS

Green DM, Lange JM, Peabody EM, Grigorieva NN, Peterson SM, Kalapurakal JA, Breslow NE. Pregnancy Outcome After Treatment for Wilms Tumor: A Report From the National Wilms Tumor Long-Term Follow-Up Study. *J Clin Oncol* [accepted].

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Sredni ST, Gadd S, Huang CC, Breslow N, Grundy P, Green DM, Dome JS, Shamberger RC, Beckwith JB, Perlman EJ, Renal Tumor Committee of the Children's Oncology Group. Subsets of very low risk wilms tumor show distinctive gene expression, histologic, and clinical features. *Clin Cancer Res* 2009 Nov 15; 15(22):6800-9.

NWTS Contact Information

Main Telephone Number: 206-667-4842
Message Line: 800-553-4878
Website: www.nwtsg.org
Email Address: nwtsg@fhcrc.org

Cell Phones

As households having telephone land lines continue to diminish we find it more and more important that we know your cell phone number(s). We request these on our annual letters, but if you have changed yours recently you can update us using the Survey Monkey link on our website or emailing us at nwtsg@fhcrc.org.

Change of Address

Have you changed your mailing address or do you plan to in the near future? Please call the message line above, 800-553-4878 or email us. Please make sure to spell your full name so that we update your information correctly. We want to make sure that we remain in contact with you and that you continue to receive our newsletters.

National Wilms Tumor Study

Fred Hutchinson Cancer Research Center
1100 Fairview Avenue N.
Mail stop M2-A876
PO Box 19024
Seattle, WA 98109