

NATIONAL WILMS TUMOR STUDY

DATA AND STATISTICAL CENTER

FRED HUTCHINSON CANCER RESEARCH CENTER

1100 Fairview Avenue N M2-A876, P.O. Box 19024, Seattle, Washington 98109

Telephone: (206) 667-4842, Message Line: (800) 553-4878, Fax: (206) 667-6623, Web: <http://www.nwtsg.org>

Which participants are eligible for the NWTS Late Effects Study (LATE)?

All on-study NWTS 1 – 4 clinical study participants who survived two or more years past diagnosis have been entered onto the Late Effects Study (LATE). Consent to be registered on the LATE study was included in the model consent forms for NWTS 1 – 4 clinical study participants. This language was not included in the model consent form for NWTS-5 clinical study participants; therefore the procedures for registering these participants on LATE are different from registration of NWTS1-4 participants.

If you have IRB approval for the LATE protocol, all of your NWTS-5 on-study participants who survived two years past diagnosis are eligible. If you would like to receive a logbook listing for these participants, please let us know at pnorkool@fhcrc.org.

If you have notified us that your NWTS-5 participants' consents included consent for long-term follow-up, we have enrolled these participants for you. If your IRB requires that you re-consent your participants to the Late Effects Study, please fax us a copy of the signed consent once it is obtained. That is all you need to do to notify us and complete enrollment.

We collect information about the status of your IRB approval for this protocol on our Participant Entry Questionnaire (PEQ). If our records show that your IRB approval is outdated or unknown, we will send you a copy of your PEQ shortly after you receive this newsletter. The PEQ form is also posted on our website, so if you believe you need to update us, please download and complete the form and fax it to us.

How often does the NWTS send out logbook rosters of participants to CRAs?

Now we send these upon request. Based upon comments at the meeting we plan to send them out twice a year. We will continue to send individual rosters upon request.

Does the NWTS provide envelopes for newsletters sent to institutions for distribution to participants?

We do not provide such envelopes. Institutions have a variety of methods to send the newsletters to participants. We ask those who's IRBs believe that sending the newsletter without an envelope presents a confidentiality breach to please use their own envelopes.

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Could the NWTS share with CRAs some of your tracking resources?

Yes, we can. There are various websites we use when we track families. Many are free resources you can easily use on the internet such as <http://www.zabasearch.com>, <http://daplus.us>, and <http://www.411.com>. We pay an annual fee to <http://www.ancestry.com> which has been useful in locating participants and confirming birth and death records. For extremely hard to find cases we pay a fee to our Tracking Resource Center at the Fred Hutchinson Cancer Research Center. For these cases it is to obtain a lead on a new address. Please contact us if you have questions about tracking strategies, for other internet resources, or if you would like to share some of your favorite websites with us.

Could the NWTS please share new contact information with CRAs if you find participants again?

For those participants who are already in direct contact with the DSC this would be difficult for us to initiate. Once a year when we send our newsletters to institutions (who then forward them to families) we sometimes have them returned to us by the post office. We will alert you when this happens and send the newsletter back to you. If you would like help in locating the family we can help you and will provide you with any new information we find. We will not contact the families without your permission.

What information does the NWTS need from an institution to contact a participant or family member?

It is helpful to have complete and accurate information on the participant's name, his/her parents'/guardians' names and their last known contact information. Any additional information such as the names of grandparents or other family members and their contact information is of equal importance. If you come across a participant who has not been seen for a while we would like to request a release so we can begin tracking the participant or family before too much more time passes.

If the NWTS finds a participant will you share the contact information with the CRA?

Our resources and staffing level prohibit us from keeping track of this level of detail and automating notices to CRAs. However, now when you receive the semi-annual logbook roster we will list all participants originally enrolled on the protocol. You will be able to identify participants who we found following the receipt of an authorized release. Please send us requests for all participants for whom you would like new contact information.