



Déjà Vu All Over Again — or “Why Am I Asked A Question More Than One Time?”

Sometimes you probably feel like the form that you just received in the mail from the National Wilms Tumor Study asks the same questions that you just answered on an earlier form. In some ways that may be true. Our goal is to obtain answers from as many participants as possible so the data will be as statistically accurate as possible in order to provide you with the most reliable information.

As we mentioned in an earlier newsletter, it is very important for us to hear from all participants, both men and women, young and old, people who have conditions to report and those who have none. Questionnaires and forms are designed to be straightforward and as quick as possible for you to complete.

One of the main reasons we ask repetitive questions is that reporting by mail is not 100% effective. Sometimes you receive a mailing and it gets buried on your desk and is never returned or is inadvertently thrown away. Sometimes after you have completed and mailed it, it gets lost in the mail. And sometimes we make a mistake and the information that you report to us is not correctly recorded. If we did not repeat our inquiry, we might miss your report of a very important event. We hope the follow-up mailing reaches you at a convenient time to complete it and put it in the return mail. New information will then be recorded and repeat information is double checked to verify if we recorded it accurately.

We do not want gaps in the information you report about yourself. We'd much rather have you tell us something twice than not at all. For example, periodically we send a Pregnancy Survey requesting you to complete a comprehensive list of all of your or your partner's pregnancies to make sure we have not missed any reports due to a lapse in contact with you.

Also, sometimes participants are in and out of contact with us. During college or at times of illness or when you bring a new baby home, your life might be too hectic for you to correspond with us. So it is important that we ask our question a second or third time to try to capture complete information.

Many of you have questions or concerns about pregnancy or fertility, and some of you have already informed us that you have been unable to become pregnant. Yet we continue to ask you about this each year. We do not intend this to be a painful reminder of something that has already been reported. Unfortunately, our resources are limited and as a result, we are unable to personalize questions on each form more than they already are. The same forms are sent to annual respondents as are sent to those who have resumed participation after a significant gap in time. We must ask questions that bring us up-to-date since we last heard from each one.

We highly regard your time and try not to waste it. We appreciate the time you take to complete and return our forms. It is important to us to be as thorough as possible so we can reliably answer your questions with scientifically accurate results.