

A BRIEF UPDATE

From the Long-Term Follow-Up Study

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<http://ltfu.stjude.org>

LTFU Study Expansion - We're Growing!

Thanks to LTFU Study participants, we have learned a great deal about the effects of treatment among childhood cancer survivors. And, we are exploring ways to improve health outcomes for these individuals. Now, the study is expanding to include people diagnosed in the more recent treatment era.

Why is the LTFU Study expanding?

Enrolling people who were diagnosed more recently will increase the number of participants and help us to better understand how treatment exposures can lead to health concerns years later. It will also give us the ability to learn about a broader range of treatments.

Who are our study participants?

Individuals diagnosed with cancer before age 21 at a participating LTFU Study center, who survived 5 years or more after they were diagnosed.

Original participants: *diagnosed 1970-1986*

- ▶ More than 14,000 active participants
- ▶ More than 3,000 siblings also actively participate in the Study

Survivors enrolled in the original "cohort" have been participating for 15 years, on average. Continuing follow-up of this group is now yielding information about late effects of treatment that develop in the fourth and fifth decades of life.

Expansion cohort participants: *diagnosed 1987-1999*

- ▶ More than 20,000 survivors have been invited to participate
- ▶ Siblings will also be included in the new group

The Study is now enrolling participants in the expansion group and some people have already returned the "baseline" questionnaire. This group of participants will help us to understand the effects of newer cancer treatments.

- The combined cohort will include more than 37,750 eligible survivors with detailed treatment information available for study. Of these, we expect that a total of 26,000 to 27,000 active survivor participants will contribute information about their health and well-being by completing the periodic Study surveys.

What do we study?

The LTFU Study has published more than 150 research papers since 2001 on a wide range of topics important for survivors, including:

- Alcohol and Diet
- Cardiovascular Function
- Chronic Health Conditions
- Complementary Medicine and Alternative Treatments
- Dental Issues
- Education, Employment, and Insurance
- Endocrine (Glandular) Function
- Genetics and Family History
- Fertility and Pregnancy
- Growth Hormone Status
- Health Status
- Healthcare Screening

Did you know? . . .

Biologic samples (such as blood and saliva) from study participants are a very important part of the LTFU Study. The samples help researchers learn about the genetic component involved in the risk of late effects. Study participants have contributed more than 12,000 blood and saliva samples so far!

- Infection
- Survivors' Knowledge of Their Cancer History
- Neurologic and Sensory Health
- Osteonecrosis (bone disease caused by interruption of blood supply to the hip or other bone)
- Physical Functioning and Quality of Life
- Psychological Health
- Pulmonary (Lung) Function
- Cancer Recurrence
- Second Neoplasms
- Sleep and Fatigue
- Smoking
- Stroke
- Sun Exposure
- Weight and Body Mass Index

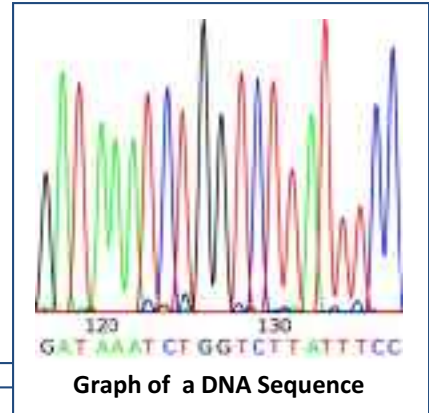
Please keep in touch with us!

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Your Participation Makes Research Work

What do our participants contribute to the LTFU Study?

1. **Your permission** to obtain medical records of your cancer treatment – these details of diagnosis and treatment exposures help us tease out the complex relationships among treatments and late effects.
2. **Your responses** to Study questionnaires help us learn about the late effects and health challenges survivors are facing.
3. **Your biologic samples** – these materials help us learn about genetic factors that may predispose some people to develop specific treatment-related health problems.
 - We ask all participants to provide a DNA sample from saliva. Previously, we collected these samples using a mouthwash “swish and spit” kit. Recently, we’ve started using the ORAGENE system to collect spit samples. It’s easier for participants and allows us to store DNA indefinitely at room temperature.
 - We ask certain participants, including people who have had a second cancer, to provide a blood sample.
 - We request tumor samples from pathology specimens of second cancers.



What benefits does the LTFU Study provide for survivors?

- Children’s Oncology Group Risk-Based Screening Guidelines – a benefit for all survivors.** Information from the LTFU Study contributed substantially to the development of the COG Screening Guidelines. The Guidelines provide detailed recommendations for ongoing health screenings based on the specific cancer treatments an individual received. They are geared toward health care professionals, but they also include a set of “Health Links” that are written in lay language. The Health Links are addressed to survivors themselves. You can find the Health Links online at:
<http://www.survivorshipguidelines.org>
- Gene Studies – a benefit for future survivors.** Your spit and blood samples are needed to help us understand how genes are involved in the risk of second cancers and other late effects. Results of gene studies may someday make it possible to design individually tailored treatments for people diagnosed with cancer in the future, based on their specific genetic make-up. Some of the gene-based research projects we are working on include studies of second cancers, obesity, skin cancer, radiation-related secondary breast cancer, and congestive heart failure.

The DNA samples from Study participants are banked indefinitely for use on projects like these, as well as for future studies. **The samples cannot be associated with your personal identifiers and we will always take care to guard your confidentiality.**

Is the LTFU Study still important, even after it has been going for so many years?

Yes, definitely! It remains very important to learn as much as we can about the life experiences and late effects experienced by childhood cancer survivors throughout their entire lives. The combined, expanded cohort allows us to extend the insights we have gained into the more recent treatment era. And it increases our ability to discover the relationships between treatments and late effects. In addition, the Study is a tremendous resource for “intervention research” – research that helps define the best ways to help survivors deal with the health challenges of survivorship. Intervention studies that have recently been conducted by LTFU researchers include the Tobacco Quit-Line study and breast and heart screening studies.

Thank you, research partners!

There is strength in numbers. Every single participant is an important contributor to this landmark Study. The LTFU Study is the largest and most comprehensive project of its kind ever conducted. Expanding the Study will increase its strength and relevance far into the future. If you’re a member of the expansion cohort, welcome! If you’re a member of the original cohort, thank you for your contributions over the years! We look forward to a continuing partnership in research with all our participants.

The next questionnaire is planned for 2013. Feel free to contact us with updates in the meantime!