

LTFU

Long-Term Follow-Up Study

Summer 2018

Update



A NOTE FROM US

As soon as a survey is returned, we begin processing it. Shown here, Aaron McDonald, PhD, the study's Project Coordinator (left) and Greg Armstrong, MD, Principal Investigator (right).

IN THIS ISSUE of the LTFU Study newsletter,

you will read about some recent exciting achievements. We are grateful to all of our participants—your dedication makes this possible. The information you contribute in your follow-up surveys provides the foundation for research that improves treatments for childhood cancers and the health of survivors.

MORE ABOUT OUR CURRENT SURVEY...

More than 13,000 surveys have been sent out so far, so we've passed the halfway mark! We are on track to mail all of the surveys before the end of 2018. A "heads-up" card in the mail will let you know when yours is on its way.

As soon as a survey is returned to us, we begin processing it. We also update our database with newly submitted online surveys each morning. It is interesting to note that the number of participants opting to complete their surveys over the phone with one of our trained interviewers has doubled

compared to the last survey, perhaps because the new survey is shorter.

Completing your survey quickly helps us get important new knowledge out to physicians and care providers. Data is usually available to researchers two or three months after the survey period ends, but the survey period can't be closed until we have received surveys from most participants. By sending back your completed surveys as quickly as possible, you will be helping us accelerate the pace of new findings and direct more funding into new studies.

With thanks, on behalf of the LTFU Study team,

Greg Armstrong, MD
Principal Investigator

Aaron McDonald, PhD
Project Coordinator

Protecting survivors' heart health

LTFU Study researchers have developed an important new tool that can help survivors of childhood cancer, and their health care providers, be more aware of their personal risk of heart attack and stroke.

Some cancer treatments increase a person's risk of developing cardiovascular conditions. Knowing your treatment-related risk can help you and your health care provider take steps to manage and protect your health.

The new Cardiovascular Risk Calculator was designed specifically for survivors who are five or more years from diagnosis ([cont. on p. 2](#))

The screenshot shows the CCSS Cardiovascular Risk Calculator interface. At the top, it says "The Childhood Cancer Survivor Study" and "CCSS Cardiovascular Risk Calculator". Below this, there is a search bar and a "Search" button. The main text describes the tool: "This risk assessment tool predicts risk of heart failure, ischemic heart disease, and stroke by age 50 among survivors of childhood cancer. It uses information from the CCSS papers, 'Individual prediction of heart failure among childhood cancer survivors' (Chow et al., ...) and 'Prediction of ischemic heart disease and stroke among childhood cancer survivors' (Chow et al., ...). These models were designed using recently completed cancer treatment information. These models have been validated using data from childhood cancer survivors: Emma Children's Hospital (Amsterdam, the Netherlands), the National Wilms Tumor Study, and the National Wilms Tumor Study." Below this, there are checkboxes for "Gender?" (Male, Female), "Patient's age at diagnosis?" (Less than 5, 5-9, 10-14, 15 or older), and "Were any anthracyclines used?" (Yes, No).

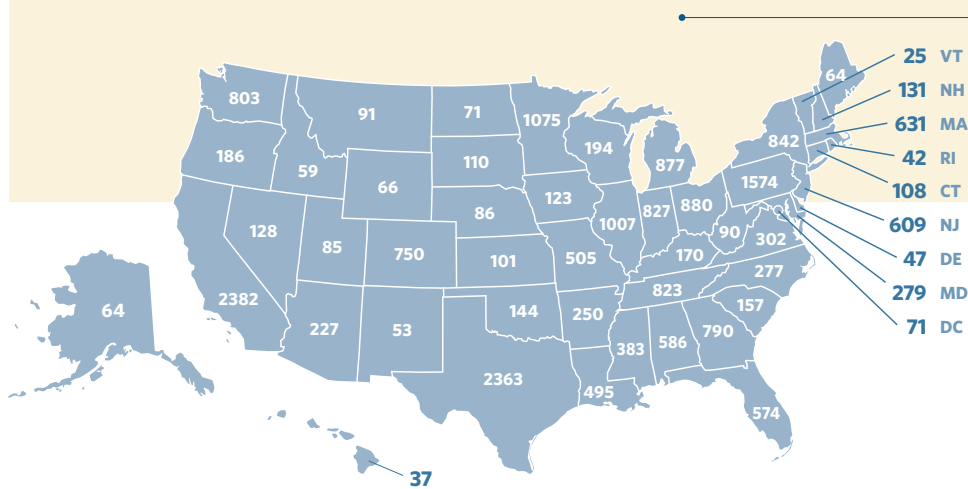
A tool for you and your provider

The new Cardiovascular Risk Calculator can help you and your health care provider assess your risk of heart disease or stroke.

ccss.stjude.org/cvcalc

The LTFU Study community

Where LTFU Study participants live (survivors and siblings)



Plus 927 in Canada



...and 42 of you live overseas

Make sure you're on the map!

Take a minute to confirm your contact information.

- Visit lfu.stjude.org and click on "Update Your Info"
- Call us toll-free at 800-775-2167
- Email us at LTFU@stjude.org

We're glad you asked...

What should I do if I'm uncomfortable answering some of the survey questions?

While our goal is to make your survey as easy to complete as possible, we understand that sometimes a question may feel too personal, or might bring up difficult feelings.

Your response to every question is important. You have the option to skip any question that makes you uncomfortable, but here are some things to consider:

Your answers help improve survivors' lives

We only include questions that we believe can make a difference in people's lives—for example, lead to new treatments or programs to promote the health of survivors. Your answers add to what we know and what we can do.

We are committed to your privacy

Every person in the study has been assigned a unique study number. When your survey responses are collected, your name and any information that could be used to identify you are removed. All of your information is confidential. The researchers involved in the study cannot disclose a participant's identity for any reason.

Protecting heart health (cont. from p. 1)

through age 50. It can tell you and your health care provider whether your risk of heart disease or stroke is low, moderate, or high, based on the treatments you received.

The Cardiovascular Risk Calculator can be accessed at ccss.stjude.org/cvcalc.

Take ownership of your health

Survivors can use this new tool to take ownership of their health and their lifestyle choices. Choosing healthy behaviors can help you maintain your heart health, and it is never too early or too late to choose a healthy lifestyle!

Read more about the calculator in the "Latest Results" section of our website: lfu.stjude.org. You also can use the site's "Health Tips" (in the Resources section) to learn more about choosing a healthy lifestyle.

JOURNAL OF
CLINICAL
ONCOLOGY

Chow EJ, Chen Y, Hudson MM, et al. Prediction of Ischemic Heart Disease and Stroke in Survivors of Childhood Cancer. *J Clin Oncol*. 2018 Jan 1;36(1):44-52. [Epub 2017 Nov 2.]

Questions or concerns?

Please call us toll-free at 800-775-2167 or email us at LTFU@stjude.org.

Read more about the study's privacy and safety policies in the "For Participants" section of the LTFU Study website: lfu.stjude.org.

Risk of breast cancer after radiation to the chest: Early menopause and hormone replacement therapy

Some female survivors who were treated for childhood cancer stop having menstrual periods, often decades before the usual age of menopause.

This is important because premature menopause may lead to a higher risk of serious health problems, such as heart disease and osteoporosis.

Hormone replacement therapy (HRT) may help survivors who experience early menopause prevent or delay age-related health problems and improve sexual function, as well as have other benefits for their quality of life. The drawback is that HRT may increase breast cancer risk, especially for women who received chest radiation. However, new LTFU research suggests that the benefits of HRT might outweigh the breast cancer risk for some survivors who experienced early menopause.

In the general population, increased exposure to female hormones has been shown to increase the risk of breast cancer. But information is lacking about the relationship between hormone exposure and breast cancer risk in survivors. LTFU researchers conducted a study to learn more about this important topic.

What we found

The researchers looked at the experiences of 1,108 female participants who received chest radiation for childhood cancer diagnosed between 1970 and 1986. They found that:

- Women who received chest radiation within one year of when they started having menstrual periods had a greater risk of developing breast cancer than those who had been menstruating for longer when they were treated.
- Early menopause decreased breast cancer risk.
- Women treated with both chest radiation and chemotherapy that impaired the function of their ovaries had a decreased breast cancer risk.
- Survivors who entered menopause before age 20, including those who were treated with HRT, had a lower breast cancer risk than premenopausal survivors.



Moskowitz CS, Chou JF, Sklar CA, et al. Radiation-associated breast cancer and gonadal hormone exposure: a report from the Childhood Cancer Survivor Study. *Br J Cancer*. 2017 Jul 11;117(2):290-299.

What does this mean for you?

HRT in survivors who experienced early menopause slightly increased breast cancer risk but not to the

same degree as the naturally produced hormones in those who continued to menstruate naturally. This new information may help survivors discuss the potential risks and benefits with their health care provider as they consider hormone replacement therapy. For some survivors, the benefits may outweigh the relatively small increase in breast cancer risk.



This new information may help survivors discuss the potential risks and benefits with their health care provider as they consider hormone replacement therapy.

—Dr. Chaya Moskowitz, Lead Investigator



In the news

On May 3, 2018, Dr. Les Robison, who founded the LTFU Study, was honored by the American Society of Pediatric Hematology/Oncology (ASPHO) for his “pioneering work in the survivorship field.” The Northwestern Achievement Award was presented to Dr. Robison at ASPHO’s annual meeting.