

# Update

## A NOTE FROM US

The information in this newsletter is provided to help you understand your CRC risk, screening guidelines, and the importance of timely screening.

We wholeheartedly encourage you to protect your health with CRC screening.

### What our research is doing

This issue highlights what LTFU Study researchers are doing to better understand childhood cancer survivors' CRC risk. The SPIRES Study is exploring how mobile health apps can be used to increase survivor and health care provider knowledge of the CRC screening recommendations.

The LTFU study is also working with survivorship researchers around the world to better understand which survivors are at risk for CRC.

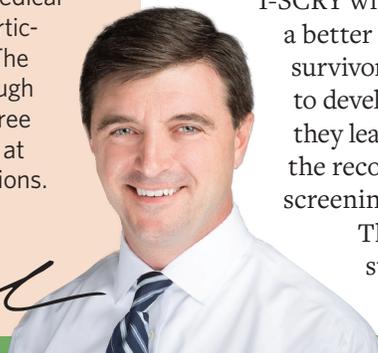
### Survey status

The information you have contributed to the LTFU Study over the years provides the basis for today's screening recommendations for childhood cancer survivors. Today, your participation is more important than ever so we can continue to advance survivorship care.

The current LTFU Study survey is available. This survey includes important topics such as health updates, unmet survivorship needs, and medical care. Print surveys are being mailed to participants who prefer it to the online option. The survey also continues to be available through your myLTFU portal. Please call our toll-free number at 1-800-775-2167 or email us at [LTFU@stjude.org](mailto:LTFU@stjude.org) if you have any questions.

We are grateful for your continued dedication and vital contributions.

Greg Armstrong, MD  
Principal Investigator

## What you need to know about... Colorectal cancer

Colorectal cancer (CRC) is the second leading cause of cancer death in the US. When diagnosed early by screening tests, CRC is more likely to be cured than cancer diagnosed after symptoms have developed during later stages of the disease.

CRC is a type of cancer that develops in the colon (large intestine) or the rectum (the section of the large intestine closest to the anus). Among the general population, screening recommendations have been adjusted because of an increase in CRC rates among younger adults. Factors like family history and lifestyle affect everyone's cancer risk. While we can't change our family history, healthy changes to diet and activity levels can decrease our risk. (See page 2 to learn more.)

### Abdominal or pelvic radiation increases risk

Everyone is at risk for colorectal cancer, but the risk is more than ten times higher for childhood cancer survivors who were treated with abdominal or pelvic radiation.

*continued on page 2*

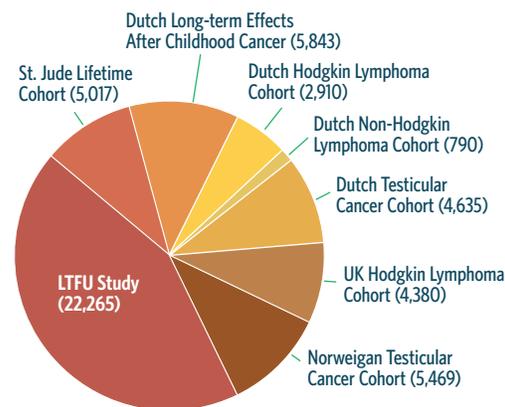
## I-SCRY: International "team science"

The LTFU Study has joined forces with seven other international research groups to learn more about CRC among survivors of childhood cancer. By merging the data from these eight cohorts, I-SCRY can analyze detailed information about treatment from more than 51,000 survivors.

### An enormous impact on survivor health

I-SCRY will give researchers a better sense of which survivors are more likely to develop CRC. What they learn may help refine the recommendations for screening, prevention, and intervention strategies.

Thanks to the participants in these groups, the results of this study could have an enormous impact on the health of childhood cancer survivors.



**I-SCRY creates a super cohort of more than 51,000 multi national survivors of childhood, adolescent, and young adult cancer.**

# ASPIRES: Increasing CRC screening

A majority of childhood cancer survivors who are at high risk for CRC are not receiving recommended screenings.



Tara Henderson, MD, Chief of Hematology, Oncology and Director of the Childhood, Adolescent and Young Adult Survivor Center, University of Chicago.

Follow-up care guidelines state that childhood cancer survivors treated with abdominal or pelvic radiation should begin screening at age 30 or five years following the radiation treatment, whichever occurs last.

“Only 37% of survivors at higher risk follow these screening recommendations,” says Tara Henderson, MD. “From previous research, we know that many survivors and their primary care providers are not aware of the increased risk and screening recommendations for survivors treated with abdominal or pelvic radiation.”

## Incorporating mobile health apps

Dr. Henderson and Karen Kim, MD, University of Chicago, lead the ASPIRES Study, which aims to find new ways to increase the number of childhood cancer survivors who get recommended CRC screenings.

ASPIRES is recruiting 315 LTFU Study participants and

their primary care providers to study whether a mobile app with text messages and videos can increase participation in CRC screening.

## “We’d love to have you take part”

“We’re enrolling randomly selected participants,” notes Dr. Henderson. “If you’ve been invited to participate, we’d be thrilled if you joined us. Even if you didn’t respond right away, we’d love to have you take part. It’s essential to find new ways for survivors to get the screening they need.”

## ...about colorectal cancer continued from page 1

### What’s my CRC risk?

Your colorectal cancer risk as a childhood cancer survivor depends on your treatment. Abdominal or pelvic radiation increases your risk of developing CRC, so you may benefit from earlier CRC screening than the general population. Your treatment records should indicate if you received abdominal or pelvic radiation treatment and when it was given.

### What are my screening recommendations?

#### Received abdominal or pelvic radiation:

Start screening at age 30 or five years after the final radiation treatment, whichever occurs last.

#### Did not receive abdominal or pelvic radiation:

Begin regular screening at age 45. (Screening recommendations may be different for people age 75 and older.)

### Screening options

Screening options include colonoscopy, which is considered the best screening test, or stool-based testing. Frequency of testing depends on your risk, prior testing results, and which screening option you choose. See page 3 to learn more about screening options and health plan coverage.

### Symptoms

Recognizing the symptoms of colorectal cancer can help you get a diagnosis and treatment as early as possible. Let your health care provider know right away if you notice any of these signs:

- Bleeding from your rectum
- Blood in your stool or in the toilet after a bowel movement
- Change in the shape of your stool
- Cramping pain in lower stomach
- Change in the frequency of bowel movements

This information is adapted from “Colorectal Cancer Following Treatment for Childhood Cancer: Are You at Risk?” (Children’s Oncology Group). Access the complete information at: [www-survivorshipguidelines.org/pdf/healthlinks/English/colorectal\\_cancer\\_Eng.pdf](http://www-survivorshipguidelines.org/pdf/healthlinks/English/colorectal_cancer_Eng.pdf)

## What you can do to... Reduce your risk of colorectal cancer



**Exercise**



**Maintain a healthy weight**



**Eat well**

**AVOID:**

**Smoking**

**Excessive alcohol**

**Processed meats**

# Explore your CRC screening options

This chart summarizes information about the most common CRC screening tests. Be sure your primary care physician is aware of your specific screening recommendations, and discuss any questions or concerns you may have.

	Colonoscopy	Stool based testing
What it is	<ul style="list-style-type: none"> <li>Procedure done by a physician to look at the colon with a camera and remove any suspicious spots</li> </ul>	<ul style="list-style-type: none"> <li>Stool test that can be completed at home and mailed to a lab for results. Most frequently used:               <ul style="list-style-type: none"> <li>- mt-sDNA (Multi-target stool DNA) test</li> <li>- FIT (Fecal immunochemical test)</li> </ul> </li> </ul>
Pros	<ul style="list-style-type: none"> <li>Recommended for higher-risk survivors who received abdominal or pelvic radiation</li> <li>Allows for immediate removal of polyps or pre-cancerous tumors and biopsy of suspicious areas for a colon cancer diagnosis</li> <li>Considered the “best test”</li> </ul>	<ul style="list-style-type: none"> <li>Recommended for average-risk survivors who were not exposed to abdominal or pelvic radiation</li> <li>Simple, convenient test that can be done at home with no prep</li> <li>If negative, can avoid colonoscopy procedure</li> </ul>
Cons	<ul style="list-style-type: none"> <li>Requires bowel prep (special diet and medication to clean the colon)</li> <li>May require time off from work and someone to drive you home</li> <li>Has a small risk of complications (this should be discussed with your doctor)</li> </ul>	<ul style="list-style-type: none"> <li>Doesn't find polyps or detect cancer</li> <li>Colonoscopy still required if results are abnormal</li> <li>Required more often than colonoscopy</li> </ul>
How it's done	<ul style="list-style-type: none"> <li>Performed with light sedation for comfort</li> <li>A small “scope” (tube with a camera attached) is inserted into the rectum to look at the colon and remove polyps or tumors</li> </ul>	<ul style="list-style-type: none"> <li>Testing kit is provided by your doctor with instructions</li> <li>Stool sample mailed by you to a lab</li> </ul>
When to test	<ul style="list-style-type: none"> <li><b>Survivors exposed to abdominal or pelvic radiation:</b> Begin testing five years after radiation or age 30, whichever is later</li> <li><b>Survivors not exposed to abdominal or pelvic radiation:</b> Begin testing at age 45 and repeat as instructed based on test results</li> </ul>	<ul style="list-style-type: none"> <li><b>Survivors exposed to abdominal or pelvic radiation:</b> Begin testing five years after radiation or age 30, whichever is later</li> <li><b>Survivors not exposed to abdominal or pelvic radiation:</b> Begin testing at age 45 and repeat as instructed based on test results</li> </ul>
Cost	<ul style="list-style-type: none"> <li>Affordable Care Act (ACA) requires health plans to cover CRC screening tests</li> <li>Usually no co-pays or deductibles</li> </ul>	<ul style="list-style-type: none"> <li>Low-cost</li> <li>Colonoscopy still required for follow-up of abnormal results</li> </ul>

## Don't let these “myths” get in the way of your recommended screenings

If you need motivation to schedule your CRC screening, remind yourself that delaying could put your health at serious risk. Here are some common misconceptions and concerns.

- 1. My health care provider says I'm too young for screening.** Many providers are not aware of some survivors' increased risk and guidelines for CRC screening. Share your treatment history with your provider, as well as the Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers ([http://www.survivorshipguidelines.org/pdf/2018/English%20Health%20Links/10\\_colorectal\\_cancer%20\(secured\).pdf](http://www.survivorshipguidelines.org/pdf/2018/English%20Health%20Links/10_colorectal_cancer%20(secured).pdf)).
- 2. Colonoscopy preparation is too hard!** Actually, prep has become easier and less demanding. For example, bowel-cleansing liquids taste better and don't require you to drink as much as previously. Changes to the dietary part of prep have also eased the process.
- 3. At-home stool testing is too gross!** The test materials are sanitary and the instructions will show you how to easily use them.
- 4. Screening is only for people with symptoms.** CRC screening helps find cancer before the person notices any symptoms. Of course, it's important to speak with your health care provider right away if you notice blood in your stool or any other changes in your bowel movements. But screening is the best way to prevent or find and treat CRC early.
- 5. No one in my family has had colorectal cancer so I'm not at risk.** Most CRCs are found in people without a family history of this cancer. Many other factors can increase your risk, like lifestyle or radiation treatment.