

LTFU

Long-Term Follow-Up Study

Stay linked to the LTFU Study:

email: ltfu@stjude.org
 phone: 1.800.775.2167

Update your contact information at:

<http://ltfu.stjude.org>



*For a list of participating centers,
 please see our website*

In this issue:

Importance of Healthy Habits

Study Updates: <i>Modifiable Risk Factors</i> for Serious Diseases	2
New Leadership, New Ways to Connect	3
Exercise: Key to Good Health	3
Making Healthy Changes	4
Online Resources	4

The LTFU Study is 20 years old! It is the world's longest-running study of survivors of serious childhood illnesses like cancer. Thank you survivors, siblings, and families, for your continuing support. We appreciate your partnership in this historic research effort.

The study has collected information from over 24,000 survivors and over 5,000 of their siblings to find out about the long-term effects of treatments for serious childhood illnesses. In addition, it has helped survivors understand the health challenges they may face and has informed them about ways to stay on top of their health. Many participants have been in the study since the very beginning, and we are still enrolling new participants so we can learn about late effects of newer treatments.

New leadership. After leading the study since its beginning, Dr. Leslie Robison is handing off the leadership to Dr. Gregory Armstrong. They have worked closely together since 2006, when the study headquarters moved to St. Jude Children's Research Hospital. Dr. Armstrong has been in charge of the study's daily operations while Dr. Robison has been responsible for overall planning and direction.



Dr. Robison (left) and Dr. Armstrong

Dr. Robison notes that after 20 years it's a good time for new leadership at the top. And he says, "Greg is the right person for the job." They'll continue to work closely together and both expect that the leadership change will be seamless. Dr. Robison will continue to take an active role in the LTFU Study. The study staff join in thanking him for his great leadership over the past two decades! He and Dr. Armstrong discuss the leadership change and share some upcoming plans for the study on page 3.

Healthy habits help survivors thrive. The importance of practicing healthy habits for survivors is the focus of this issue of the newsletter. While survivors can't change the fact that they were treated for a serious childhood illness, there are many ways they can help themselves stay healthy. The research presented in this issue brings home the reality that staying in control of your health by practicing a healthy lifestyle really does make a difference. Not smoking, being physically active, achieving and maintaining a healthy weight, and keeping up-to-date with recommended health screenings can reduce your risk of developing a serious health condition like heart disease or stroke. As a bonus, these habits can also increase your enjoyment of life!

On page 4, we offer some ideas for making positive changes in health behaviors, together with encouragement from a survivor who has successfully lost weight and made a significant improvement in her health and wellbeing.

Please watch for the next follow-up survey, which we recently started mailing. We hope you'll take the time to update us on your health.

Would you like to receive the LTFU Study newsletter by email?

Let us know where to send it!

1. Go to <http://ltfu.stjude.org>
2. Click on "Update Your Info" in the menu bar at the top of the screen.
3. Type in your contact information, including your email address (which will only be used by LTFU staff).
4. Check the box that says you'd like to receive the newsletters by email.

Study Updates

Healthy Habits Are Especially Important for Survivors

The importance of healthy habits for survivors has been underlined by findings from two recent studies done by LTFU Study researchers. The studies looked at *modifiable* risk factors that can increase the chances of serious heart disease or stroke for childhood cancer survivors.

What are modifiable risk factors? A *risk factor* is something that raises your chance of developing a disease. Risk factors can be personal traits like age or sex. Certain treatments you received may also be risk factors for disease.

For example, radiation therapy and anthracycline chemotherapy drugs like daunorubicin or doxorubicin are risk factors for heart disease, even though they're needed to cure some childhood illnesses.

Some common lifestyle-related conditions are also risk factors for diseases. The conditions listed in the box below are risk factors for serious heart disease and stroke. They're called *modifiable risk factors* because they can often be prevented or modified by changing our habits.

Conditions that Are Modifiable Risk Factors for Serious Heart Disease or Stroke

- ➔ High blood pressure
- ➔ Diabetes
- ➔ Obesity
- ➔ High levels of cholesterol and other fats in the blood

What these conditions have in common is that they can occur with aging, they can be side effects of some cancer treatments, and they can be treated. In addition, making healthy lifestyle changes such as losing weight, quitting smoking, or becoming more active, can make a big difference in modifying the impact of these conditions on your chance of developing serious heart disease or stroke.

First Study: Modifiable risk factors and major cardiac events

In the first study, a team led by Dr. Greg Armstrong examined the effects of modifiable risk factors such as high blood pressure on survivors' chances of developing a serious heart condition.

The study team looked at the following major heart conditions that survivors and siblings reported on the questionnaires:

Coronary artery disease: *Damage to the blood vessels that supply blood and oxygen to the heart. It can be caused by narrowing of the arteries due to fatty deposits and by inflammation*

of the vessels. Coronary artery disease is a major cause of heart attacks.

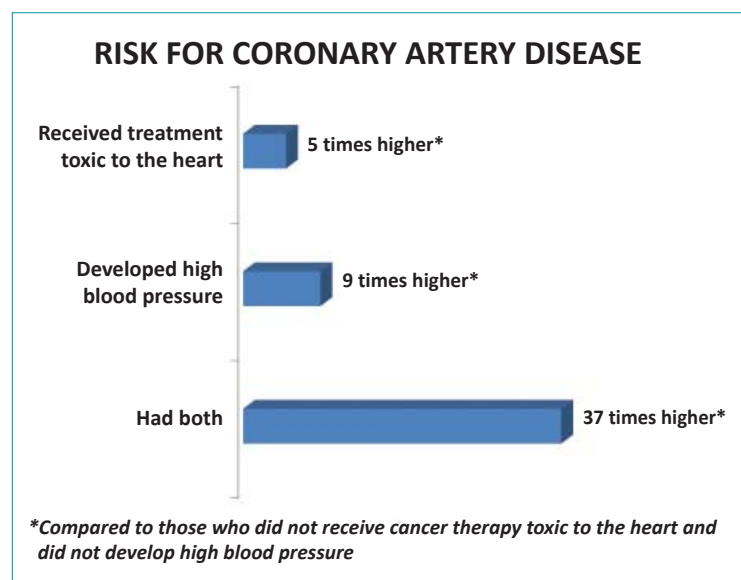
Heart failure: *Damage to the heart muscle that makes the heart unable to pump adequately.*

Heart valve disease: *Damage to the valves in the heart that causes them to leak or to become stiff and narrow so that blood backs up in the heart.*

Arrhythmia: *Problems with the heart beat. Arrhythmia can result in the heart beating too slowly, too fast, or in an irregular way.*

Here's what they learned:

- The chance of developing heart disease was greater than expected for survivors who received treatments linked to heart damage and who later developed one of the modifiable conditions, *especially high blood pressure*.
- As shown in the chart below, survivors who received toxic treatment to the heart and who developed high blood pressure in adult life had the highest risk for coronary artery disease.



Additionally, survivors who reported a modifiable risk factor also had higher risk of heart failure, valve disease, and arrhythmia.

Dr. Armstrong hopes these dramatic and somewhat surprising results will motivate survivors and their healthcare teams to make sure survivors understand the importance of practicing healthy habits. Survivors should receive regular testing for high blood pressure, diabetes, and other treatable conditions that put them at risk of serious heart conditions.

The results of this study were published in the *Journal of Clinical Oncology* 2013; 31(29):3673-80.

Second study: Stroke risk in childhood cancer survivors



Dr. Sabine Mueller
led the study

The second study looked at brain radiation, atherosclerosis, and stroke risk in survivors. *Atherosclerosis* is the buildup of fats on the inner walls of the blood vessels. It is the most common risk factor for stroke in the U.S. adult population. In addition, it is known to be linked to radiation therapy. Atherosclerosis may be preventable and it can be treated.

The research team compared 292 childhood cancer survivors who reported having a stroke with siblings similar in age. On average, the survivors were more than 23 years from the time of their cancer diagnosis.

They learned that . . .

- Survivors were at least 8 times more likely to have a stroke than siblings.
- Survivors who had received brain radiation had a higher risk of stroke compared to survivors who had not received brain radiation. The more radiation they received the greater the risk.
- Survivors who had high blood pressure or diabetes—which are risk factors for atherosclerosis—were at increased risk of having a stroke. Survivors who had high blood pressure had a 4-fold increased stroke risk; the risk for African Americans was even higher.

The team concluded that . . .

- Risk factors for atherosclerosis like high blood pressure and diabetes contribute to the risk of stroke for survivors.
- Survivors who had brain radiation should be tested for high blood pressure and treated if they develop the condition.
- A better understanding of the relationships between brain radiation, atherosclerosis risk factors, and long-term stroke risk is crucial so effective stroke prevention strategies can be developed for childhood cancer survivors.

Dr. Sabine Mueller, the leader of the research team, is an LTFU Study investigator at the University of California, San Francisco. Study results were published in the *International Journal of Radiation Oncology* 2013: 86(4):649-55.

New Leadership, New Ways to Connect

As he hands over the leadership of the LTFU Study to Dr. Greg Armstrong after 20 years, Dr. Les Robison notes that “Dr. Armstrong and I have worked hand-in-glove for most of a decade. The LTFU Study has achieved a lot in that time and this is a good time to bring in new leadership.” Dr. Robison will continue to work closely with Dr. Armstrong to make sure the study provides survivors with tools to achieve the best health possible.

Looking back at the past two decades, Dr. Robison says, “The LTFU Study has really made history for both survivors and health care providers. Thanks to you, our amazing participants, we’ve been able to gain precise information about the health of survivors as they age. The information you’ve provided has helped us to set up detailed guidelines for follow-up health screenings for survivors. The knowledge we’ve gained has also led to improved treatments for new patients.”

Dr. Armstrong adds, “Because of what we’ve learned from participants, you might say the study now works like an early warning system for aging for survivors. Our findings may help them maintain their health as they age.”

Looking forward, Dr. Armstrong says, “The study will only get stronger as the data from an additional 10,000 participants who were treated in a more recent era becomes available for researchers this Fall.

“We will also be trying out new ways of communicating with our participants, for example through mobile phones using text messaging and “apps” or phone applications. The goal is to make it easier to share research results with participants and for them to share their information with us.”

Dr. Armstrong, Dr. Robison, and the study team are committed to building on the great results achieved so far. Thank you, study participants, for being our dedicated, long-term partners in this work!

Exercise is a master key to health. It can help you . . .

- Maintain a healthy weight
- Prevent and control high blood pressure
- Prevent and control diabetes
- Keep cholesterol levels healthy

If you'd like to be more active, ask your doctor about how to get started with activities that are right for you.



Making Healthy Changes

The basic recipe for a healthy lifestyle is pretty well-known: Eat a balanced diet with lots of vegetables, fruits, and fiber; limit calories from fat; don't overeat; don't smoke; stay active and exercise for 30 minutes on most days; get a good night's sleep; limit alcohol use, and manage your stress. The findings reported in this newsletter show that these good habits are especially important for survivors, who may be at risk of serious disease if they develop common lifestyle-related conditions like high blood pressure, diabetes, obesity, or high cholesterol.

But realistically, people don't always make healthy lifestyle choices, and they often have mixed feelings about changing old habits. Overeating, smoking, or being inactive may provide comfort and a feeling of being in control. On the other hand, it takes effort, commitment, and sometimes a painful struggle to replace unhealthy habits with healthy ones.

Motivation is key to making successful changes. And motivation is personal, it's the thing that makes you tick. Once you find *your* motivation, you're on your way! Below are some ideas for making healthy changes that some people have found useful.

- For many people, another person is their motivation for change. Ask someone you trust to help you as you make new habits.
- Think about a time you successfully made a change. What did you do and how did you feel? You did it once, you can do it again.
- Be a critical observer of your own behavior and thoughts. You don't have to believe it when you tell yourself it's no use!
- Change one small thing at a time—say going to bed or getting up 10 minutes earlier than usual. Allow success to build up your self-confidence.
- Use the power of routine. Set up regular times to practice your new habits.
- Use the power of NOW. When you're feeling discouraged or overwhelmed try getting up and doing one thing.
- Never be afraid or embarrassed to start over—again. You'll be glad you stuck with it.
- Before starting a new diet or exercise program be sure to check in with your health care team!

We would love to hear about your experiences making healthy habits. If you'd like to share with us, please send an email to:

ltfu@stjude.org

What Worked for Elisa



Elisa Franco knows she needs to take care of her health. She knows the treatments she received as a child to cure her brain tumor might put her at risk for health problems down the road. Right now, though, she's more concerned with looking good and feeling great. She's learned that exercising and being careful about what she eats help her do both.

Elisa is a high-school senior from Valencia, California, near Los Angeles. Standing just 4 feet 9 inches tall, and with a taste for sweets, she recently decided she wanted to lose some weight in order to look and feel her best. To keep things simple she started out by using some pre-packaged protein meals and vitamins. She also got serious about exercise. Elisa works out at the same gym as her mom, fitting in an hour of exercise on most days.

She does both strength training to build muscle and “cardio”—exercises that work her heart. She's been at it for a month and has lost six pounds so far.

Elisa has some weakness in her left side and balance is an issue for her. “It's easier for me to walk when I'm lighter,” she says, “and I have so much more energy inside.” It's also easier for her to wear the fashionable clothes she loves.

Elisa is looking forward to a busy senior year, and to going on to college next year, where she plans to major in interior design. Beyond that? “I want to live for a long time!” she says.

By finding her personal motives to take charge of her health Elisa is helping herself to make that wish a reality.

Online Resources

www.heart.org/HEARTORG/GettingHealthy/GettingHealthy_UCM_001078_SubHomePage.jsp

Diet and exercise resources, smoking cessation, and stress management tools from the American Heart Association.

www.nutrition.gov/nutrition-and-health-issues/heart-health

Nutrition, recipes, information on exercise, some resources in Spanish, some geared toward specific groups such as African-Americans.

<http://smokefree.gov>: Strategies for quitting smoking that can apply to changing any habit.