

LTFU

Long-Term Follow-Up Study

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Make sure you receive your newsletter and other Study materials. Update your contact information anytime it changes.

- Go to our website (www.ltfu.stjude.org).
- Click the link [Update Your Info](#) in the menu bar at the top of the screen.
- Update your address and telephone numbers. Also give an e-mail address, if you have one.



For a list of participating centers,

see our website:

www.ltfu.stjude.org

Keep a move on ...

Fall 2009

To keep healthy, we need to keep moving. Here's why. Regular physical activity keeps our muscles and bones strong. It also boosts our mood and keeps our minds sharp. In addition, exercise *may* make it easier to stay at a healthy weight, when it goes hand-in-hand with a healthy diet.

Survivors and physical activity.

The benefits are even greater for adults who had a serious illness like cancer during childhood. For them, regular physical activity may help to cut down, slow down, or stop many treatment late effects. Because exercise is key to health for all of us, we focus on it in this issue of your LTFU Study newsletter.

On page 2, we bring you the latest on what we've learned about LTFU Study participants and exercise. In her comments, Dr. Hudson explains what the results mean for you and what can be done with what we have learned.

Don't miss "Notes from Survivors" where a survivor tells how he moved on in life after osteosarcoma and amputation of a leg. Today, he inspires others to keep moving in his job as a personal trainer.

If you are inspired and want to get moving again, see page 4. Kiri Ness, PhD, a physical therapist and investigator in the Long-Term Follow-Up Study, shares tips for building an exercise program from the ground up.

Enjoy this issue and *keep moving*.

—Margaret Carbaugh, Managing Editor

FREE Help to Quit Smoking

In our Study Update on exercise (page 2), we report that smoking is linked to an inactive lifestyle. For this and other health reasons, we want to remind you of a FREE program to help smokers quit.

Last year we invited smokers in the Study to take part in the program. At the time, you may not have been ready to make a quit attempt. The study is still open to enrollment so don't miss your chance to find out more and sign up!

For more details, call 1.877.4SJ.QUIT or visit our web page:

www.stjude.org/breakfreefromsmoking



Study Updates

Physical Activity among Study Participants

Adults who had cancer or a similar illness during childhood can't change the facts of their medical diagnosis or the treatments they had. But they may decrease the risk of treatment late effects by changing the way they live now. In addition to reducing late effects, something as simple as regular physical activity can stop serious health conditions down the road.

To find out about physical activity among Study participants, two research teams reviewed information provided by Study participants through LTFU surveys. We report the results below. Dr. Hudson explains how they apply to you and what can be done about them (see page 3).

What we learned. Despite the known health benefits of physical activity, one research team found that many adult survivors in the LTFU Study lead inactive lives. They are also less physically active than members of a sibling comparison group. The study team—led by Kiri Ness, PhD—based its findings on questionnaire responses of 9,301 survivors and 2,886 siblings in the comparison group.

Ness's team found one striking result. Almost a fourth (23%) of those in the survivor group did not take part in any leisure-time physical activity in the previous month. Contrast this to 14% for the sibling group. Study participants who had medulloblastoma and osteosarcoma were the most inactive.

The issues that influence survivors are complex. One study team concluded that a “one size fits all” approach to getting them more active will not work.

Another study team looked at the same issues, but from a different point of view. This team was led by Cheryl Cox, PhD. Cox's team focused mostly on modifiable predictors of physical activity. By modifiable predictors, we mean those traits or factors that a person can change. Examples of modifiable factors are fear, anxiety, and motivation. Study participants expressed fears about their future health, return of their cancer, or the discovery of a health problem during a routine physical exam.

Cox's team also identified some risk factors that have been reported before. These include lower education level, pain, and fatigue. The factors affected how often and how hard survivors exercised. They also affected whether survivors exercised at all.



Cheryl Cox led the other study team.



Kiri Ness led one study team. She explains the importance of being physically active to a recent participant in her study.

Factors Influencing Physical Activity

From the first study:

- Those who had medulloblastoma or osteosarcoma reported the highest level of inactive lifestyles.
- Treatment with cranial radiation or amputation was also linked to an inactive lifestyle.
- Health factors linked to an inactive lifestyle were being underweight or overweight, smoking, and having symptoms of depression at the time the survey was completed.

From the second study:

- Survivors are more likely to begin a program of physical activity or to keep exercising if their doctor encourages them to do so.
- Fear and anxiety may cause a survivor to cut back on how often or how hard he exercises.
- Treatment late effects such as pain and fatigue can cause a survivor to reduce how often or how hard he exercises.

In general, Cox's team found that a large number of factors have some bearing on whether survivors take part in physical activity. Because the issues that influence survivors are complex, the study team concluded that a “one size fits all” approach to getting survivors more active will not work.

To find out more. Details of both studies were published in the journal *Cancer* (February and May 2009).

To read more about exercise among LTFU Study participants, see the Spring 2008 issue of the LTFU Study newsletter.

You can find the newsletters on-line at:

www.ltfu.stjude.org/newsletters

Moving Past Roadblocks to Physical Activity

Adults who had cancer or a similar illness during childhood have more to gain from exercise than do those who never had a serious childhood illness. Yet they are less likely to be physically active than are other adults. Thanks to the studies reported here, we know more about the reasons why.

Some of our findings are what you might expect (summarized in text box, page 2). Adults who had cancer of the bone or those who underwent a limb amputation are less active than are others. The same was true of overweight or underweight adults or those who experience depression.

Results are important because they tell health care providers which groups of adult survivors they need to target with health-promoting messages and programs to get them up and moving. By knowing who is at risk, we can also help newly diagnosed patients. For example, patients who had medulloblastoma and cranial radiation are at high risk for an inactive lifestyle as adults. We might prescribe a rehabilitation program from which children can benefit now that will also encourage physical activity as they get older.

Results of both studies also point to ways that survivors can help themselves. The first step is for survivors to become aware of the factors that may influence their own behavior and make them more likely or less likely to exercise. For example,

some survivors may be held back by fear. Someone who has undergone an amputation, for instance, may be afraid of falling. To get over his fear he can talk to a physical therapist to find out what types of exercise he can safely do. Other survivors who are inactive also report that they are in pain. They need to get help to address their pain before they can be successful long-term in an exercise plan.

We also found that the doctor-patient partnership can have a strong influence on whether survivors start a program of physical activity and stick with it. This means that doctors should spend time teaching survivors about the benefits of exercise and assist in making referrals to physical therapists or others qualified to work with them. As always, survivors have their part to play in this partnership. They need to share details of their medical history with all members of their health care team and speak up about their health fears and worries.



Notes from Survivors

Moving on in Life After Childhood Cancer and an Amputation

Dave Michael inspires others to keep moving in his role as their personal trainer. It's a good job for someone who has never liked to stand still for very long.

As a kid Dave excelled in baseball and basketball. He enjoyed all types of rough-and-tumble sports, including football and snow-skiing. None of that stopped when doctors found that he had osteosarcoma, a bone tumor. When chemotherapy didn't shrink the tumor, Dave, then 12, opted for amputation rather than risk the cancer coming back in some other part of his body.

After his amputation, Dave learned to shoot baskets with one hand while leaning on a crutch with the other. In baseball, he shifted to a spot as warm-up pitcher. He also took up a new sport—wrestling—and was elected team captain.

"When I started my own program, I had to figure out what I could do safely," he says. He already knew about his current health because he has annual checkups with a late effects specialist at Children's Memorial in Chicago. To learn how the muscles work, he took courses in human anatomy. He also talked with his doctors, who helped him with his program.

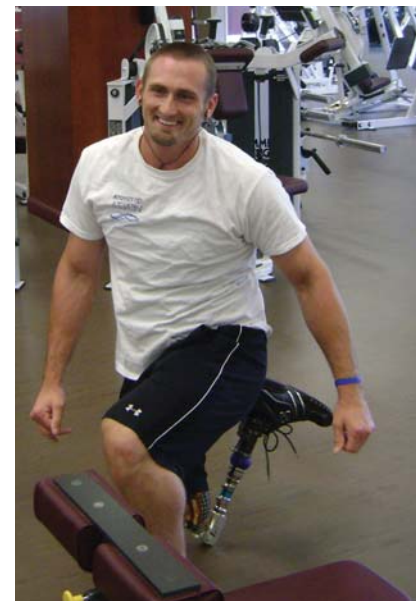
As a trainer, Dave now works with two other men who had amputations. He based their programs on what has worked for him. "I stress core strength because it keeps the person stable as he's moving," says Dave. "It also helps him move without hiking up his hip."

Dave's experiences have given him an unexpected edge with other clients. "I take away their excuses," he says. When a client lags behind in his program, Dave tells him: "If I can do an exercise with just one leg, you should be able to do it with four good limbs!"

Several years ago Dave won two gold medals in national competitive events. One was for the long jump; the other was for the shot-put. He recently earned top honors in a rock climbing event at the Extremity Games.

Dave also raises funds to send athletes with disabilities to sports competitions. His future goal is to open a gym designed for those with a disability. "A lot of gyms are handicap-accessible," he says. "But they are not necessarily designed for someone in a wheelchair or a person who has a prosthesis."

To read more about Dave and the non-profit organization he helped to start, go to: www.super-gimp.org



Dave Michael

Exercise Your Options

Exercise is for everyone. But not every exercise is for you. This is especially true if you have been inactive for a while.

Medical Clearance

The first step in starting an exercise program is to get medical clearance. Your current health and previous cancer treatment may affect what exercise options are best for you. Plus there are often concerns by both physicians and survivors about what exercises are safe.

For example, some survivors have been told that it is not safe for them to exercise because they received treatment with drugs that can weaken the heart muscle. Even they can benefit from some type of physical activity. A thorough check-up is important to identify any restrictions on specific types of exercise. Here are a few examples of medical issues that may influence the best or safest exercise:

- ✓ **Foot drop:** Jogging may not be a good exercise for survivors with weak ankles. Stationary biking may be a safer option.
- ✓ **Internal prosthesis (endoprosthesis):** Contact sports may increase the risk of injury to an internal prosthesis. But regular exercise can reduce the risk of injury by keeping muscles and joints flexible and strong. Good exercise choices for individuals with an endoprosthesis are swimming and walking.
- ✓ **Weak heart or lungs:** Individuals with a weak heart or lungs will not be able to take part in heavy exercise. Yet even they can exercise. They will need to start at a slow pace and take more breaks.

Start where you are.

- Have you been inactive for a while?
Set smart and safe goals. Don't expect to run a 5K in a few months. But you can walk part of the race.
- Start with a low-impact exercise.
Even low-impact exercises can benefit your heart and lungs. They stretch your muscles and make them more flexible. Yoga and tai chi are good choices.
- Build your exercise program slowly.
Exercising too heavily or too long can lead to soreness and injury.



Build exercise into your daily life.

- *At home:* Don't use the remote. Get up and change the channel.
- *At work:* Walk up a flight of stairs and park farther away from your building.
- Make an exercise date with your friends in lieu of a movie.

You may stand up your exercise program but you won't stand up your friends.

- Don't forget your "best" friend.
Your dog needs exercise too. Walk him for 20 or 30 minutes twice a day.

Do what you like and what's safe.

- Some people like to run, bike, and lift weights. Others enjoy swimming or dancing.
- In cold or rainy weather, drive to a large store and then walk around inside it.
- Some people can't jog around the block because traffic is too heavy to be safe. Get an exercise video and dance in your living room instead.

Mix it up!

- All exercise programs for survivors should have three parts. Make sure yours includes:
 - ✓ **Flexibility** (stretching) exercise to keep joints and muscles warmed up
 - ✓ **Aerobic exercise** to benefit your heart and lungs
 - ✓ **Weight training** to keep muscles and bones strong
- To keep things fun, run or walk two days in the week. Go to yoga class one day and lift weights on the other days.

Work with somebody who has experience with childhood cancer survivors.

- To find someone, go to the website of the American Physical Therapy Association.
<http://www.apta.org>
- Interview more than one physical therapist.
Ask whether the person has worked with adults who had cancer or other serious illness during childhood and your specific disease.