Here’s to your health! As someone who has successfully overcome a serious illness, your perspective on health may be quite different from that of many people. We realize that you value your health and do not take it for granted. Reviewing and analyzing the information you have provided as part of the Long-Term Follow-Up Study has confirmed what we had hoped. The overall health of the participants is good and most participants want to know what steps they can take to stay active and healthy. In this issue you will find information we think can help you do just that. Everyone is “at risk” for some kind of health problem, whether it is heart disease, breast cancer, brittle bones, or something else. Medical research can help us determine if our individual risk is higher than that of others and, if so, what we can do to either bring that risk down or detect problems before they are too serious. Being “at risk” for a certain disease, or finding something about yourself in a table does NOT mean that you will get that disease. These things can remind us of our need to pursue a healthy lifestyle, however. Truly, knowledge is power, and acting on that knowledge is everyone’s best bet for continued good health. We hope that in this newsletter you will find something that can contribute to your health.

On page two of this issue, you will find an article about Mark Miller, a study participant who developed heart trouble in his early 40s that was likely treatment-related. Information about long-term treatment effects is not widely known among primary care doctors; however, Mark was persistent in informing his doctors about his treatment history and about his suspicions that his symptoms were related to it. Fortunately, he was correctly diagnosed after some false starts. On page two, we also present the results of a recent analysis of smoking habits of study participants. The serious health risks of smoking are well-known. For survivors of childhood cancer and similar illnesses these risks can be multiplied because their hearts or lungs may already be weakened by the treatment they received for their illness. Finally, on the back page you will find a chart describing risk factors for common treatment-related health problems. The chart also includes a list of healthy activities you can practice to help reduce your risk.

Website update. If you have access to the internet, we invite you to visit our study website. We recently revised the main page. We added links to other sites that have resources for childhood cancer survivors. We also plan to post a list of frequently asked questions about the study and about cancer survivorship, as well as other information of interest to study participants. The website address is www.cancer.umn.edu/ltfu.
Long-Term Follow-Up Study researchers have completed an analysis of cigarette smoking in our cohort. For this study, they looked only at the information provided by participants who were over age 18 when they completed their first (baseline) study questionnaire.

When comparing study participants to members of the general US population, the researchers found that our participants are less likely to smoke than other Americans are. And, if they do smoke, they are more likely to quit. These findings are encouraging. They indicate that study participants are aware, in general, of the risks of smoking.

However, the rate of smoking among participants remains far too high. The researchers found that 28 percent, or about one fourth, of participants were smokers or former smokers (had smoked at least 100 cigarettes in their lifetime). In addition, 17 percent, or one in six, reported that they currently smoked.

The investigators also discovered that study participants are not nearly as aware as they need to be about the added health risks they may face as a result of therapies they received for their childhood cancer or similar illness. In fact, participants who received therapies that have been found to be associated with heart problems or with lung problems were about as likely to smoke as participants who did not receive these types of therapies.

Treatments that can cause lung damage include the chemotherapy drugs Bleomycin, BCNU (also know as Carmustine), and CCNU (also know as Lomustine). Anthracycline chemo drugs, including daunorubicin (Daunomycin), doxorubicin (Adriamycin), and idarubicin can damage the heart. So can radiotherapy to the chest and to the spine, and total body radiation. Total body radiation is often given before a bone marrow transplant. If you received any of these therapies, it is important for you to let your doctor know.

The results of this study serve as a reminder of the dangers of smoking, especially for individuals treated for cancer and similar illnesses. If you don’t smoke, don’t start. If you do smoke, quitting is
one of the most important things you can do to maintain and improve your overall health. Talk to your doctor about quitting. He or she can work with you to design an individualized program to help you succeed. Additional resources for quitting smoking are listed at right.

The smoking study was led by Dr. Karen Emmons of the Dana-Farber Cancer Institute in Boston, MA. The results were recently submitted for publication.

Benefits of quitting smoking*

❤ 20 MINUTES AFTER QUITTING
Blood pressure drops to a level close to that before the last cigarette.

❤ 8 HOURS AFTER QUITTING
Carbon monoxide level in the blood drops to normal.

❤ 24 HOURS AFTER QUITTING
Chance of heart attack decreases.

❤ 2 WEEKS TO 3 MONTHS AFTER QUITTING
Circulation improves; lung function increases up to 30%.

❤ 1 TO 9 MONTHS AFTER QUITTING
Coughing, sinus congestion, fatigue and shortness of breath decrease; cilia regain normal function in the lungs, increasing the ability to handle mucus, clean the lungs, and reduce infection.

❤ 5 YEARS AFTER QUITTING
Stroke risk is reduced to that of a nonsmoker 5-15 years after quitting.

❤ 10 YEARS AFTER QUITTING
Lung cancer death rate is about half that of a continuing smoker’s. Risk of cancer of the mouth, throat, esophagus, bladder, kidney, and pancreas decrease.

❤ 15 YEARS AFTER QUITTING
Risk of coronary heart disease is the same as a nonsmoker’s.

* From the American Cancer Society

Resources for quitting

Involve your family and your doctor. Your most essential resources for quitting smoking are your family and friends and you medical care provider. Smoking is an addiction and quitting takes all the support you can get. Listed below are some additional sources of education and support.

On-line resources:
www.surgeongeneral.gov/tobacco/
Very specific tips for getting ready to quit and how to handle the first week. Also has information on myths that can keep you from quitting.

www.cdc.gov/tobacco/how2quit.htm
Downloadable booklets, including one geared toward teenagers that has lots of useful information for people of all ages.

www.lungusa.org/tobacco/
Tips to help you get the most out of using anti-smoking medications and for staying smoke-free.

www.nicotine-anonymous.org/
Focuses on the addictive nature of nicotine. Offers a twelve-step program modelled on Alcoholics Anonymous and emphasizes support group meetings. Lots of on-line literature.

If you don’t have access to the Internet: These national groups offer educational materials, usually free, on how to quit smoking:

American Cancer Society
1-800-ACS-2345

American Heart Association
1-800-AHA-USA1

American Lung Association
1-800-LUNG-USA

Office on Smoking and Health
1-800-CDC-1311

National Cancer Institute
1-800-4-CANCER

Our Mailing Address Is:
Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware Street SE, MMC 715
Minneapolis, MN 55455

Toll-Free Phone: 1-800-775-2167

Website: www.cancer.umn.edu/ltfu

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Staying healthy: Know your risk

People who were treated for childhood cancer and similar illnesses may have an increased risk of getting certain health problems as they grow older. Three common problems that can occur are heart disease, breast cancer, and osteoporosis, a condition in which the bones become weakened and prone to fracture. You can take steps to reduce your chances of getting these problems:

- **First**, you should know the risk factors for these conditions and find out which ones, if any, apply to you.
- **Second**, inform your doctor about your potential risk.
- **Third**, be sure to practice good health habits – eat a balanced diet, exercise, don’t smoke, or quit smoking.

Risk factors for osteoporosis, heart disease, and breast cancer are listed below, along with healthy actions you can take to minimize your chances of getting them.

### OSTEOPOROSIS

**General risk factors:**
- Whites and Asians
- Family history of osteoporosis
- Females

**Treatment risk factors:**
- Steroids like prednisone or dexamethasone
- Methotrexate
- Radiation therapy
- Treatment causing ovarian or testicular (gonadal) failure

**NOTE:** Treatment increases risk for both males and females

**Things that can increase your risk:**
- Low calcium in diet
- Smoking
- Having an inactive lifestyle
- Drinking alcohol excessively
- Lack of weight-bearing exercise

**Things to do to reduce your risk:**
- Eat at least 4 servings of calcium-rich foods daily. Non-fat milk, yogurt, cheese, almonds, broccoli and oranges all contain lots of calcium.
- Do at least 20 minutes of weight-bearing exercise everyday - walking, running, even vacuuming counts! Be sure to talk to your doctor before beginning an exercise program.
- Get regular check-ups to see if you need calcium or vitamin supplements or stronger medicines to prevent bone mineral loss.
- Don’t smoke - or quit smoking.
- In cases of gonadal failure, consider hormonal therapy to aid bone health.

### HEART DISEASE

**General risk factors:**
- African-Americans
- Family history of heart disease

**Treatment risk factors:**
- Doxorubicin (Adriamycin)
- Daunorubicin (Daunomycin)
- Idarubicin
- Radiotherapy to the chest or spine
- Total body radiation
- Young age at treatment, especially younger than 4 years old

**Things that can increase your risk:**
- Smoking
- Overweight
- High fat in diet
- Lack of exercise
- Diabetes
- High blood pressure
- High cholesterol

**Things to do to reduce your risk:**
- Don’t smoke - or quit smoking.
- Maintain a healthy weight.
- Limit fat in the diet - no more than 30% of calories is a good guideline.
- Exercise regularly - at least 3 times a week for 20-30 minutes. Be sure to talk to your doctor before beginning an exercise program.
- Get regular check-ups with periodic heart tests
- Keep blood pressure, cholesterol, and blood sugar in control with diet or medication as recommended by your doctor.
- Promptly report symptoms of heart problems to your doctor. Symptoms include shortness of breath, difficulty breathing, chest pain, especially associated with fainting, dizziness, sweating, or nausea.

### BREAST CANCER

**General risk factors:**
- Females
- Family history of breast cancer

**Treatment risk factors:**
- Chest radiotherapy
- Increased risk with increasing doses of radiotherapy to the chest area

**Things that can increase your risk:**
- Early start of menstruation (younger than 11-13 years)
- Not having children
- Late age at menopause
- Overweight
- Possibly, hormonal replacement therapy (This has been studied mostly in older, post-menopausal women.)
- Possibly, high fat in diet
- Possibly, high alcohol intake

**Things to do to reduce your risk:**
- Perform monthly breast self-exams.
- Report possible signs of breast cancer promptly to your doctor. Symptoms include lumps felt on self exam, skin changes on the breast, like dimpling or thickening, and abnormal fluid discharge from the nipple.
- Maintain a healthy weight
- Limit fat in the diet - no more than 30% of calories is a good guideline.
- Drink alcohol only in moderation, if at all.
- **For women who received chest radiotherapy:**
  - Have a doctor examine your breasts twice a year.
  - Begin periodic mammograms no later than 10 years following chest radiotherapy or as recommended by your doctor.
Are you at risk for breast cancer?

If you had radiation therapy to your chest or adjacent areas to treat your childhood cancer or a similar illness, you may be at increased risk of breast cancer. If you are unsure about what treatments you received, contact the doctors where you were treated to find out what your treatment was. Breast cancer is one of the most common cancers among women and is highly curable, especially if detected in early stages.

Chest radiation given for certain childhood cancers may have included all or some portions of the breasts. Chest radiation was commonly used for the following conditions:

- Lymph gland cancers like Hodgkin’s disease or non-Hodgkin’s lymphoma
- Soft tissue tumors arising in the chest wall or ribs, like Ewing’s sarcoma
- Cancer that spread to the lungs from other organs, like Wilms’ tumor.

What are the risk factors for breast cancer?

Breast cancer is the most common cancer in women except for skin cancer. Research has indicated that the risk of breast cancer is increased for women who:

- Are older, especially over 40 years old
- Have a family history of breast cancer or genes known to be related to breast cancer risk. (Less than 10 percent of women with breast cancer have one of the known genes, however.)
- Have an early onset of menstruation
- Have a late onset of menopause, at age 55 or older
- Are older than 30 years when they have their first child
- Have never given birth.

Some studies have suggested that women who drink more than 10 grams of alcohol (about 1 mixed drink or glass of wine) per day, are obese or eat high-fat diets may also be at increased risk. In addition, taking hormones like estrogen or birth control pills may increase breast cancer risk, but this has not been confirmed.

How does your treatment affect your risk?

Your chances of developing breast cancer after chest radiation may be influenced by several factors:

- **Sex** - Women are much more likely than men to develop breast cancer after radiation therapy.
- **Radiation dose** - The higher the dose of radiotherapy to the chest area, the higher the risk of developing breast cancer.
- **Age at treatment** - Some studies have suggested that girls radiated during puberty may have a higher risk.
- **Family history** - Women in families known to carry gene changes that predispose to breast cancer may also have a higher risk.

The risk of breast cancer becomes elevated five to nine years after treatment and continues to rise after 10 years. This means that girls and women treated for childhood cancer or similar illnesses are often diagnosed with breast cancer at much younger ages (about 30 to 40 years old) than are women in the general population, who are usually diagnosed at age 50 or older.

If you are at increased risk, ask your doctor to:

1) Review your treatment history with you and, if possible, follow up with the center where you were treated to obtain additional information. Knowing your history can help your doctor estimate your risk.

2) Show you how to perform a thorough breast self-exam and help you develop an appropriate breast cancer screening schedule. A complete breast cancer screening program includes self-exam, a clinical exam by your doctor twice a year, and periodic breast x-rays (mammograms).

3) Discuss your health habits with you and inform you how to practice healthy behaviors that minimize the risk breast cancer.

If you or your health care provider would like more information, please call our toll-free study line:

1-800-775-2167

The Long-Term Follow-Up Study is coordinated by the University of Minnesota and supported by a grant (U24 CA55727) from the National Cancer Institute of the National Institutes of Health.
STAYING HEALTHY: HELP YOURSELF!

PRACTICE A COMPLETE BREAST SCREENING PROGRAM

Breast cancer is a curable disease when it is detected in its early stages. Regular screening, including periodic mammograms, can save your life.

Perform monthly breast self-exams. Ask your healthcare provider to show you how to do the exams and inform you about the best time of month to do them.

Report signs of breast cancer promptly to your doctor. These include lumps, dimpling or thickening of the skin, and abnormal fluid discharge from the nipple.

IF YOU RECEIVED RADIATION THERAPY TO THE CHEST:

Have a doctor examine your breasts twice a year.

Begin periodic mammograms no later than 10 years following radiation therapy to the chest.

After age 40, you should have a mammogram every year.

KNOW YOUR FAMILY HISTORY OF BREAST CANCER

Inform your doctor if your mother or any of your aunts or sisters had breast cancer before age 50.

MAINTAIN A HEALTHY WEIGHT WITH A DIET THAT IS LOW IN FAT

Eat a variety of FRUITS and VEGETABLES - 5 or more servings per day.

Eat a variety of grain products, including WHOLE GRAINS. Choose 6 or more servings a day.

Get your protein from FISH, beans, FAT-FREE and LOW-FAT milk products (yogurt, cheese, cottage cheese, milk), skinless poultry, and lean meats.

Choose fats like OLIVE OIL with 2 grams or less of saturated fat per serving.

Long-Term Follow-Up Study
www.cancer.umn.edu/ltfu
Know Your Risk of Heart Disease
AFTER TREATMENT FOR CHILDHOOD ILLNESS

Important information for you and your health care provider from the Long-Term Follow-Up Study

Are you at risk for heart disease?
If you had anthracycline chemotherapy or radiation therapy to treat your childhood cancer or similar illness, you may be at increased risk of heart problems as you grow older. If you are unsure about what therapies you received, contact the doctors where you were treated to find out what your treatment was.

Anthracyclines. Anthracycline chemotherapy includes drugs like doxorubicin (Adriamycin), daunorubicin (Daunomycin), and idarubicin. Many years after receiving high doses of these drugs heart damage can develop, causing weakened pumping of the heart muscle. This condition is known as cardiomyopathy. It can lead to heart failure in severe cases.

The risk of heart failure is related to the dose of anthracycline received. Keeping the dose below 300 mg/m² has reduced the rate of cardiomyopathy following chemotherapy to less than five percent. However, children and adolescents treated with low doses of anthracyclines may have “subclinical” heart injury, that is, heart damage that cannot be detected by heart screening tests.

Radiation therapy. The heart is usually in the radiation field when radiation is delivered to the chest, the spine, or the left side of the torso. Of course, the heart is also in the radiation field when total body radiation is given before a bone marrow transplant.

Radiation can injure the heart muscle, valves, or blood vessels. Doses of more than 3000 cGy can cause the heart muscle to become stiff. This lessens its ability to pump. Radiation can also cause the heart valves to become leaky and stiff. Sometimes, these conditions progress to heart failure.

Radiation may also cause scarring in the coronary arteries, the blood vessels that feed the heart. This increases the risk of blockage by fatty deposits circulating in the blood stream (atherosclerosis). Once blood flow to an area of the heart is severely blocked, pain (angina) develops and the heart muscle tissue in the blocked area may die. This condition is called a myocardial infarction (heart attack).

Other risk factors. Chemotherapy drugs like cyclophosphamide (Cytoxan), ifosfamide, and amsacrine can aggravate heart damage caused by anthracycline chemotherapy and radiation therapy.

Your chances of developing heart problems after treatment are also increased if you received treatment at a young age, especially younger than four years old. In addition, treatment can increase the chance of developing heart problems for females and for people with Down syndrome.

Finally, pregnancy and childbirth and strenuous exercise such as weight training can strain a heart that has been weakened by treatment or other factors. It is important to get a doctor’s advice before becoming pregnant or starting an exercise program.

If you are at increased risk, ask your doctor to:

1) Review your treatment history with you and, if possible, follow up with the center where you were treated to obtain additional information. Knowing your history can help your doctor estimate your risk.

2) Get records of any previous cardiac evaluations you have had.

3) Recommend regular medical check-ups and periodic heart tests if you were treated with anthracycline chemotherapy or radiation involving the heart.

4) Be aware that most adults who are survivors of childhood cancer and similar illnesses have normal heart function on examination and routine screening tests such as echocardiogram and electrocardiogram. Despite this fact, undetected injury may make them vulnerable to early onset of heart disease.

5) Promptly evaluate persistent symptoms that may indicate heart problems even though serious heart disease may not be an expected occurrence.

6) Discuss your health habits with you and inform you how to practice healthy behaviors that reduce the risk of heart disease, such as getting regular exercise and eating a heart-healthy diet.

If you or your health care provider would like more information, please call our toll-free study line: 1-800-775-2167

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STAYING HEALTHY: HELP YOURSELF!

**Talk to Your Doctor About Medical Conditions That Can Affect Your Heart**

Keep **blood pressure, cholesterol, and blood sugar** in good control with diet or medication as recommended by your doctor.

If you are **pregnant**, tell your doctor about the treatment you received for your childhood illness.

**Don’t Smoke! If You Do Smoke, Quit!**

Talk to your doctor about the many resources that are available to help you quit.

**Don’t Use Cocaine or Other Recreational Drugs**

**Maintain a Healthy Weight With a Heart-Healthy Diet**

The American Heart Association recommends that you:

- Eat a variety of **fruits and vegetables** - 5 or more servings per day.
- Eat a variety of grain products, including **whole grains**. Choose 6 or more servings per day.
- Get your protein from **fish**, beans, fat-free and low-fat milk products (yogurt, cheese, cottage cheese, milk), skinless poultry, and **lean** meats.
- Choose fats like **olive oil** that have 2 grams or less of saturated fat per serving.

**Get “Hooked” on Exercise**

Move vigorously for **20-30 minutes** at least three times a week - every day is even better.

Do things you like - walk, ride your bike, golf, dance.

Please be sure to check with your doctor before starting an exercise program!

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Long-Term Follow-Up Study

[www.cancer.umn.edu/ltfuf](http://www.cancer.umn.edu/ltfuf)
Are you at risk for osteoporosis?

Some therapies used to treat childhood cancer and similar illnesses can increase the risk of osteoporosis. Osteoporosis is a silent bone disease that usually does not cause symptoms in the early stages. People with osteoporosis have thin and weak bones that are prone to fracture. If you received any of the therapies mentioned in this brochure you may be at risk of early onset osteoporosis that can lead to bone fracture. If you are unsure about what treatments you received, contact the doctors where you were treated to find out what your treatment was.

How does osteoporosis develop?

From childhood to young adulthood, our bodies accumulate bone mineral to strengthen and build bones. As we grow older, the amount of bone mineral deposited slows down. After age 30 to 35 years we begin to lose bone mineral. Bone loss continues throughout the remainder of life. If bone production early in life is not adequate, osteoporosis can result, and can lead to bone fracture.

What are the risk factors for osteoporosis?

Osteoporosis is often thought of as a disease exclusively of older women. Osteoporosis does most often occur in older people, but bone mineral loss occurs in both men and women. In addition, people in the following groups have an increased risk of developing osteoporosis:

- Women who have stopped having menstrual periods
- Men with low testosterone levels
- People who have had radiation to the head and people who have low levels of growth hormone
- Members of the white or Asian race
- People with a family history of osteoporosis.

Personal habits that increase risk are:

- Eating a diet that is low in calcium
- Having an inactive (sedentary) lifestyle

- Smoking cigarettes
- Drinking alcohol excessively.

How does your treatment affect your risk?

Cancer treatment can increase your risk of getting osteoporosis for many reasons. And it can make it possible for you to get this disease at any age, whether you are a man or a woman. Because osteoporosis has no visible symptoms at first, it is especially important to be aware of your risk and to take the needed steps to prevent it.

Chemotherapy. Several chemotherapy drugs can prevent bone mineral from getting into bones. The main drugs that have this effect are: prednisone, methotrexate, ifosfamide, dexamethasone, and cyclosporine.

Radiation therapy. Bones treated with high doses of radiation often lose bone mineral. Also, radiation to the brain, ovaries, or testes can reduce the production of hormones like growth hormone, testosterone and estrogen that are needed to build bone.

Other treatment-related risk factors. During therapy, cancer patients often are not able to eat well or exercise regularly. Exercise, particularly weight-bearing exercise, and good nutrition throughout life are vitally important in preventing osteoporosis.

If you are at increased risk, ask your doctor to:

1) Review your treatment history with you and, if possible, follow up with the center where you were treated to obtain additional information. Knowing your history can help your doctor estimate your risk.

2) Based on his or her review of your treatment history, discuss the advisability of doing a bone density test.

3) Recommend mineral supplements and/or medications if needed to strengthen your bones.

4) Discuss your health habits with you and inform you how to practice healthy behaviors that reduce the risk of osteoporosis - or the risk of fracture if you have osteoporosis.

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Staying Healthy: Help Yourself!

Talk to Your Doctor about Bone Health

Get regular medical check-ups to find out if you need calcium or vitamin supplements, or prescription medications to prevent bone mineral loss.

Ask your doctor about a diet and exercise plan.

In cases of gonadal failure (like premature menopause), consider hormonal therapy to help maintain bone health.

Eat a Balanced Diet that Has Enough Calcium and Vitamin D

Young adults need 1000–1500 mg of calcium every day. Try to get 4 servings of calcium-rich foods a day. Good choices are:

- 8 oz. of milk (300 mg),
- 2 oz. of cheese (200–300 mg),
- 1 cup of yogurt (400 mg),
- 1 cup of broccoli (50 mg),
- 1 orange (50 mg).

You need vitamin D to absorb calcium. Chances are you get plenty of vitamin D from your regular diet and from sunlight. Too much vitamin D is harmful, so don’t take any supplements without asking your doctor.

Do Weight-Bearing Activities for at Least 20 Minutes Everyday

Walking, jogging, dancing, and aerobics are all good choices. So is weight training. But anything that gets you on your feet helps, including housecleaning, gardening, and climbing stairs.

Please be sure to check with your doctor before starting an exercise program!