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Long-Term Follow-Up Study

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UNIVERSITY OF MINNESOTA
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From the editor

Tumors of muscle. In the Fall 2004 newsletter we reported on the results of two LTFU studies of bone tumor survivors. In this issue we focus on another group of study participants, those who were diagnosed with childhood rhabdomyosarcoma (RMS). RMS is a rare type of tumor that develops in soft tissues like muscle. In the US, only about 350 children are diagnosed with this disease each year. Because RMS is so uncommon and because the tumor and treatment can lead to significant physical problems and limitations, RMS survivors sometimes report feeling isolated and alone. We have been happy to find that, in spite of the difficulties people who had RMS may face, most of our study participants are coping very successfully in their adult lives. Please see the article on page 2 for details.

Family medical history - a tool for healthy living. Family medical histories are an important tool that can help you and your health care provider anticipate health problems you could be at risk of developing. Examining patterns that occur among your relatives can give your doctor important clues about illnesses that might "run in your family." The US Surgeon General recently started a Family Health History Initiative to encourage everyone to learn more about their family's health history and to assemble a medical "family tree." According to LTFU Study investigator Dr. John Mulvihill:

"Although 'genetic test' has come to mean a laboratory assay of the gene. . . , the truth is that one of the best gene tests, available to all clinicians, is the targeted and proper family medical history."

Such a "targeted" family medical history can be especially useful for survivors of childhood illnesses like cancer, tumor, or leukemia. In this issue of the newsletter we have included a form that you can use to begin developing your own family medical history to share with your health care provider. The article on page 3 discusses this topic in more depth.

And finally . . . Please see the back page for news about some LTFU Study participants, an update from the ACOR discussion lists, and more.

Inside

Rhabdomyosarcoma survivors	2
Know your family health history	3
Update from ACOR discussion lists	4
Notes from participants	4
Parent and survivor conference	4

LTFU study toll-free phone number:
1-800-775-2167

Focus on rhabdomyosarcoma survivors

by Dr. Melissa Hudson

In this issue of the LTFU newsletter we continue to report on the health of particular groups of survivors. Last time we looked at the bone tumor group. This time we feature two recent studies focusing on survivors of pediatric rhabdomyosarcoma (RMS). About 600 individuals who are currently participating in the LTFU Study were treated for RMS. It is the most common soft tissue cancer seen in childhood. This type of cancer may develop in the soft tissues around the ear or eye, or in pelvic organs like the bladder and prostate. It may also develop deep in the abdomen or in an arm or leg.

Over the last 30 years, cure rates for children with RMS have steadily improved using intensive treatments including surgery, combination chemotherapy, and in some cases radiation therapy. In recent years, the success of this approach has allowed doctors to use less aggressive surgeries and preserve organs like the eye and the bladder.

Dr. Judith Punyko led the research team for these two studies. They used information shared by LTFU Study participants who had RMS to find out how often medical problems occurred in the group and if these problems affected individuals' physical and social functioning in adult life.

Long-term medical effects of cancer treatment.

In the first study, researchers identified the most common health conditions survivors reported. They studied when and why these problems were most likely to occur. Most people in the group (71 percent) were younger than 10 years old when they started cancer therapy. The majority (77 percent) were treated with surgery, chemotherapy, and radiation therapy. Between one-fourth and one-third of patients reported problems affecting their eyes, ears, heart, lungs, brain, nerves, or endocrine (hormone-producing) glands.

The risk of late medical complications was strongly related to the location of the tumor and the type of treatment. For example, survivors treated with radiation for a head and neck tumor often developed eye problems like cataracts or chronic dryness. They were also more likely to have low

levels of the hormones that control growth, puberty, and thyroid function. Some problems were more likely to start during or shortly after therapy, while others did not show up for many years. For example, survivors reported eye problems soon after treatment; hormone deficiencies were more likely to occur more than five years after diagnosis. Knowing when problems are likely to occur is important so that action can be taken to correct or prevent them. This study will be published later this year in the journal *Pediatric Blood and Cancer*.

Impact on physical and social function in adult life.

The second study looked at how well LTFU participants who had RMS are doing as adults. About 400 RMS survivors who were 18 years or older participated in this study. The research

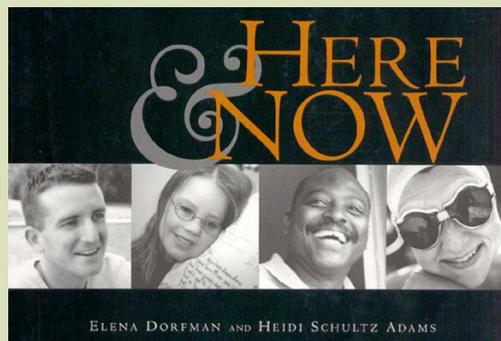
team judged physical functioning by whether individuals reported conditions that harmed their appearance or their physical abilities, problems that affected their stamina and ability to take care of themselves, or a health problem that prevented them from working or going to school. They graded social functioning by whether individuals completed high school, had ever worked a job, or had ever been married. The good news is that the majority of people in the study were doing well: 92 percent had completed high school, 97 percent had entered the work force, and 85 percent were currently married or living as married.

Overall, however, the RMS survivors did have poorer physical functioning than brothers and sisters their same age. They were six times more likely to report physical problems, most often affecting appearance, and two times more likely to report problems

with physical functioning. RMS survivors with functional problems or cancer-related pain were less likely to complete high school than the members of the sibling comparison group. Also, they reported a greater rate of special education services due to missing school or having problems with learning or concentrating.

The results of this study show that RMS survivors generally adapt very well during adulthood, but the vast majority (85 percent) experience at least some long-lasting physical and functional changes associated with their treatment.

OF INTEREST . . .



HERE & NOW, by Elena Dorfman and Heidi Schultz Adams, New York, 2002.

Available at bookstores, libraries, and online booksellers.

Author Elena Dorfman, who was diagnosed with childhood RMS, compiled these inspiring stories of cancer survivors as her "postscript to cancer."

What should survivors and their doctors learn from these studies?

Successful treatment of childhood rhabdomyosarcoma requires an aggressive approach that combines several types of treatments - surgery, combinations of chemotherapy drugs, and sometimes radiotherapy. This "multi-modal" approach provides the best chances for long-term cure. Even though recent advances have resulted in less radical surgery and safer radiation techniques, the intensity of therapy needed to control this disease often results in physical and functional problems for long-term survivors. These problems may have a negative effect on the individual's social functioning and quality of life in adulthood. Identifying who is at greatest risk of having problems and when problems are most likely to appear helps doctors provide more timely assistance to people who are struggling with physical and social complications after cancer. Some individuals may need to seek physical therapy or rehabilitation services to help them improve their functioning and increase their physical and social well-being. The studies reporting the long-term progress of RMS survivors participating in the LTFU Study are remarkable because they indicate excellent adjustment in adulthood in spite of having to deal with frequent medical complications and physical problems.

Editor's note

These studies are some of the largest ever to look at the health and well-being of RMS survivors. This disease (like the bone cancers we discussed in a previous newsletter) can develop in many different parts of the body so it is hard to draw a simple picture of how it affects the people who have survived it. Some will have relatively minor troubles resulting from their disease and treatment. Others must deal with life-altering problems like amputation, chronic pain, or disfigurement. No study can measure an individual's personal hardships and struggles. For some people on some days the price they have paid to be cured may seem too high. Nevertheless, these studies show that, like participants in the other groups we have studied, the vast majority of RMS survivors are successfully coping with life's challenges. We salute you and all our participants for your courage.

Know your family health history!

You already know that it is important for your physician to know your medical history. Did you know that it may be just as important for him or her to know your family's health history? Many times, this information can help identify health conditions that you or your children may be at increased risk for in the future. Family members share genes that have an effect on the risk of common health problems like heart disease, stroke, diabetes and cancer.

Whether you develop these conditions is not just related to your genes. It is also related to your health habits as well as to exposures we all experience to harmful agents in the food, water and air in the environment. We can't change our genetic make-up and we have little control over environmen-

tal exposures. Practicing healthy behaviors, however, like eating a healthy diet, exercising regularly, and not smoking can help reduce the risk of developing health problems. If certain illnesses tend to "run in families," your doctor may also suggest screening tests that can detect disease and cancer at an early, more treatable stage. That is where knowing your family health history comes in.

Last fall the United States Surgeon General, Dr. Richard Carmona, began the Family Health History Initiative to increase awareness about the role that genes and heredity play in predicting future health. Dr. Carmona encouraged everyone to learn about their family history by asking questions and talking at family gatherings. He recommended that you collect health information like major medical conditions and causes of death, the age that diseases started, the age of death from disease, and ethnic background. Be sure to ask about all close relatives including grandparents, parents, aunts, uncles, nieces, nephews, brothers and sisters. You can use the form included in this newsletter to make a record of the family health information and share it with your doctor. After reviewing your family health history, your doctor can decide if you are at risk for specific health problems and recommend lifestyle changes and screening tests.

After you outline your family history, date it and file it in a safe place. Be sure to share a copy with your doctor, who can recommend screening tests and ways to reduce the risk of health problems that may run in your family. If your doctor can't answer questions about it, ask for a referral to a genetics doctor or counselor to help understand your health history. Update the record every few years. Holiday gatherings are a good time to get updates about health events of family members. You may want to provide a copy of your family history with other members of your family, as well.

FAMILY HEALTH HISTORY: CONDITIONS TO RECORD

1. YOUR ORIGINAL CANCER OR SIMILAR ILLNESS

Type/name of disease? Your age when diagnosed? Location of the cancer on your body? Did it spread? Where did it spread? Was there a second cancer in another part of the body?

2. YOU AND YOUR FAMILY

- Cancer, tumors, leukemia
- Deafness at an early age
- Blindness at an early age
- Glaucoma
- Thyroid problems
- Heart attack/bypass surgery
- High cholesterol
- High blood pressure
- Blood clotting problems
- Bleeding problems
- Stroke
- Seizures
- Asthma
- Cystic fibrosis
- Kidney disease
- Diabetes
- Sickle cell disease
- Thalassemia
- Multiple miscarriages or stillborn babies
- Chromosome abnormalities
- Learning disabilities
- Mental retardation or developmental delay
- Mental illness
- Alcoholism
- Arthritis at a young age
- Easily broken bones
- Any other conditions you think might run in your family

Update from the ACOR discussion lists

The Association of Cancer Online Resources (ACOR) provides a place online where long-term survivors of childhood cancer, tumor, and similar illnesses can share their experiences. Many LTFU Study participants have taken part in these discussion lists since we placed a link to ACOR on the LTFU Study website. Linda Zame, ACOR's founder, reports:

It's been an eventful year since the first announcement of the internet discussion group for long term survivors. The LTFU newsletter essay on our group brought many new members and voices over the course of the year that add to our overall knowledge and experience of feeling known and understood. If you would enjoy the experience of talking to other long term survivors, please come join us at the LT-Survivors discussion group. We are a vibrant and vocal group and we look forward to hearing from you.

**- Linda Zame, founder, moderator for LT-Survivors
(zame@earthlink.net)**

Linda also sent us the following comments from Meg, an ACOR list participant who had childhood RMS:

I had a rhabdomyosarcoma on my soft palate when I was 11. . . . In 37 years, I have yet to meet anyone who had a soft palate rhabdomyosarcoma. I can barely open my mouth, my teeth give me trouble, my ears drive me nuts, and I am embarrassed by my nasal voice. I will carry the baggage . . . until the day I die.

But, as for all childhood cancer survivors, there is the other side, too. I've lived my life with awareness since I was 11 years old. I am not troubled by statistics – the worst can always happen, but usually it doesn't. My husband and I have two healthy children and we make it a habit to appreciate the joys of just living. I breathed a sigh of relief when my kids both passed their 11th birthdays, and my hope is that cancer never touches our lives again.

In addition to the long-term survivor group ACOR also has groups that focus on specific cancer diagnoses. If you would like to participate in one of these discussion lists you can link to them from the LTFU Study website:

www.cancer.umn.edu/ltfu

Notes from study participants

Minnesotan **Paul Erdahl** was 20 years old and a junior in college when he was diagnosed with embryonal rhabdomyosarcoma. The tumor was discovered in his left middle ear. He remembers feeling somewhat out of place

while being treated on the pediatric ward. "There were times when I was older than the other three patients in the room put together," he says. Paul has worn a hearing aid for a number of years but fortunately has not experienced many other serious effects of his illness.

For several years, Dr. Erdahl - who earned his PhD in counseling psychology - worked with people with chronic diseases, helping them to adapt and cope with their disabilities. Currently, he is an executive in leadership development for a major health care corporation. It has been 25 years since he was diagnosed with RMS, and "I've finally gotten to a point that I don't think about it all the time," he says.

Jill and Andrew Sprawson of Ontario are LTFU Study participants who were diagnosed with brain tumors as children. They are also married to one another! When



Mr. and Mrs. Sprawson

Andrew reached adulthood he found that the effects of his illness and treatment made it hard for him to find a job. He started his own successful business but found that something was still missing in his life. After volunteering with a number of organizations, he started a group to provide support and networking for adult survivors of childhood cancer. The group is called Rebounders Canada and its motto is "Thrive rather than just

survive." Andrew met Jill, his wife and fellow survivor, through Rebounders and today they are proud parents of two young boys.

Rebounders Canada works to put survivors in touch with one another. They produce a quarterly newsletter, organize and run fundraising events, and alert members about survivorship get-togethers, family camps, and conferences. The Rebounders Canada website has additional information on the group's many activities. To find them online go to:

www.rebounders.ca

Parent and survivor meeting

The International Confederation of Childhood Cancer Parent Organizations (ICCCPO) is hosting a meeting that may interest LTFU Study participants. The meeting will be held in September in Vancouver, BC, as part of the annual meeting of the International Society of Paediatric Oncology (SIOP). There will be workshops for both parents and survivors. Dates for the conference are September 20-24, 2005. Additional information about the meeting can be found online at: www.icccpo.org. You may also call the LTFU Study toll-free number: **1-800-775-2167**.

WHOM SHOULD I TALK WITH?

To get the most accurate health history information, it is important to talk directly with your relatives. Explain to them that their health information can help improve prevention and screening of diseases for all family members.

Start by asking your relatives about any health conditions they have had - including history of chronic illnesses, such as heart disease; pregnancy complications, such as miscarriage; and any developmental disabilities. Get as much specific information as possible.

It is most useful if you can list the formal name of any medical condition that has affected you or your relatives.

You can get help finding information about health conditions that have affected you or your family members -- living or deceased -- by asking relatives or health care professionals for information, or by getting copies of medical records.

If you have children or are planning to have them, you and your partner should each create a family health portrait and show it to your health care professional.

Knowing your family health history is a powerful guide to understanding risk for disease. However, keep in mind that a family history of a particular illness may increase risk, but it almost never guarantees that other family members will develop the illness.

MOST IMPORTANT

Parents
Brothers and Sisters
Your Children

ALSO IMPORTANT

Grandparents
Uncles and Aunts
Nieces and Nephews
Half-Brothers and Half-Sisters

OBTAIN IF YOU CAN

Cousins
Great-Uncles and Great-Aunts

HOW DO I FILL OUT THE FORM?

The "My Family HealthPortrait" form (see other side of this sheet) will help you collect and organize your family information. **No form can reflect every version of the American family, so use this chart as a starting point and adapt it to your family's needs.**

First, write each of your relatives' names in the designated boxes and circle whether they are male (M) or female (F). On the next line, write the name of any health conditions they have had. If you know the age at which they were diagnosed with a condition, write that in parentheses after the condition. For example: "diabetes (diagnosed age 37)."

If family members have died, write "deceased" and the age at which they died, for example "heart attack (deceased age 63)."

For twins, write "twin" on the first line for both individuals. If the twins are identical write "identical twin" on the first line for both.

If your family includes half brothers

or half sisters, write "half brother" or "half sister" on the first line and note "different father" or "different mother" on the next line.

Some conditions are more common in people with a shared background or ancestry. It is important to record the ancestry of your relatives and be as specific as possible. For example, if you know that your grandmother is Hispanic and her family comes from Mexico, write "Mexican" underneath her name. Likewise, if your family is from Africa, Asia, Europe or South America, note the country they came from, if possible.

Once you complete the form, take it to your health care professional so that he or she can better individualize your health care. Be sure to make a copy for your records and update it as circumstance change or you learn more about your family's health history.

Congratulations on taking this step toward a longer, healthier life! "My Family Health Portrait" can be an effective way to improve your health -- today and in the future.

You may want to make several copies of this form to practice with. We encourage you to update it each year during the holidays or whenever your family gets together. Please call our toll-free study line if you have any questions about using this form: 1-800-775-2167.

-- LTFU Study Staff

Thank you to the U.S. Surgeon General's Office for this Family History Portrait.
For more information, visit the Surgeon General's Family History website:

www.hhs.gov/familyhistory/

Name: _____

Date: _____

My Family Health Portrait

