

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA
Summer/Fall 2000

University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
Seattle Children's Hospital & Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Health Care - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
Riley Hospital for Children-Indiana University
UAB/The Children's Hospital of Alabama
University of Michigan-Mott Children's Hospital
Children's Medical Center of Dallas

The Long-Term Follow-Up Study is now on the World Wide Web, hosted by the University of Minnesota's Cancer Center, at www.cancer.umn.edu/ltfu. Currently, the site contains back issues of the newsletter, as well as an article that gives an overview of the study. In that article you will find a discussion of the Childhood Cancer Survivor Study (CCSS), which is a part of the Long-Term Follow-Up Study. You may also come across the term CCSS in papers published by or about the study. As you know, the Long-Term Follow-Up Study is a multi-institution study, funded by the National Cancer Institute, of people who were treated for cancer, leukemia, tumor, or a similar illness during their childhood or adolescence. The CCSS is limited to Long-Term Follow-Up study participants who had a confirmed diagnosis of cancer. It also includes approximately 3,500 brothers and sisters of participants, who serve as a comparison group for the study. (Researchers call these individuals the "sibling control" group.) We hope this clears up some of the confusion that may have been caused by references to the CCSS. We hope you enjoy the website and visit it often. We will be adding new information to the site as it becomes available.



The University of Minnesota Comprehensive Cancer Center hosts the Long-Term Follow-Up Study on its website.

The articles in this issue deal, in one way or another, with the topic of risk. On page 4, Dr. Joe Neglia, a pediatric oncologist at the University of Minnesota, writes about how to interpret reports about risk factors that may affect your health. Results of a recent

continued on page 2

Inside

Survivor's guide	2
Thyroid problems after Hodgkin's disease	3
Understanding risk	4

continued from page 1

analysis of thyroid problems in study participants who had Hodgkin's disease are presented on page 3. We also discuss an excellent new book (see below) that provides in-depth information about the health risks faced by childhood cancer survivors and about steps that can be taken to minimize those risks. The book is called *Childhood Cancer Survivors: A Practical Guide to Your Future*, by Nancy Keene, Wendy Hobbie, and Kathy Ruccione. Kathy is a pediatric oncology nurse at Children's Hospital Los Angeles, and a Long-Term Follow-Up Study investigator.

We hope you enjoy the newsletter. Everyone on the study staff wishes you a healthy, happy, and "risk-free" season.

Survival guide

With the publication of the new book, *Childhood Cancer Survivors: A Practical Guide to Your Future*, by Nancy Keene, Wendy Hobbie, and Kathy Ruccione, people treated for childhood cancer have an important new tool to help them manage their health and minimize their risk of late effects of treatment. The book is one of a series of Patient Centered Guides published by O'Reilly & Associates, Inc. It includes both comprehensive technical information in easy-to-understand language and an abundance of survivors' stories written in their own words. The authors all have first-hand experience with childhood cancer. Nancy Keene is the mother of a leukemia survivor; Wendy Hobbie and Kathy Ruccione are pediatric oncology nurses who coordinate follow-up programs.

The first part of the book deals with the impact of childhood cancer on the emotional life and relationships of individuals and families, especially at critical times like the end of therapy and

the transition from adolescence to adulthood. The second part of the book is organized into chapters on the various body systems and the late effects associated with each. There is also a chapter (Chapter 6) describing the most common childhood cancers, their treatments, and related late effects. Tables listing the recommended follow-up tests for each type of cancer treatment can be found in this chapter, as well.

In an interview with the authors posted on the publisher's website (address below), Kathy Ruccione states,

"Long-term survivors sometimes get ahold of information about the range of possible late effects and assume it applies to them. In fact, it's a very individual matter. This underscores how important it is for parents and survivors to keep records of their illness and treatment."

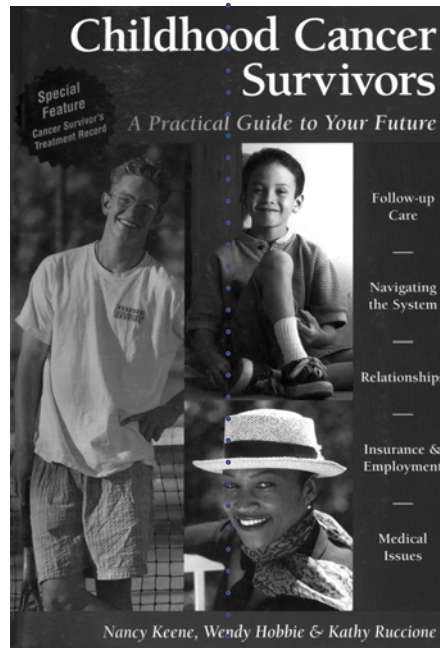
One great feature of the book is the pull-out Treatment Record that can be used to do just that. The authors encourage people to ask their oncologist or nurse practitioner to fill out the treatment record. Complete and

accurate treatment information can help survivors and their healthcare providers know what late effects to watch for, as well as those they probably don't have to worry about.

The open way in which the individuals in this book share their thoughts and feelings will undoubtedly be of great help to readers who may feel isolated by their experience with cancer. Commenting on *Childhood Cancer Survivors*, one woman calls the guide "our" book, not something written for doctors or nurses, but for

us. It talks our talk, deals with our issues, and faces reality head-on with the gutsy manner of survivors themselves."

Childhood Cancer Survivors is avail-



able at most large bookstores, or you can check with your local library. If your library does not have the book, they will probably be willing to order it. For more information about the book or the authors, or to order directly from the publisher, go to the publisher's website, www.patientcenters.com, or call their toll-free number: 800-998-9938.

Study update: Thyroid problems after Hodgkin's disease

Children and adolescents treated for Hodgkin's disease have an excellent prognosis and most will go on to become long-term survivors. However, like all cancer survivors, they are at risk for certain delayed effects of their treatment. Among the most common late effects associated with treatment for Hodgkin's disease are abnormalities of the thyroid gland. Long-Term Follow-Up Study investigators recently completed an analysis of thyroid problems reported by 1791 study participants who were treated for Hodgkin's disease. The experience of these individuals was compared to that of both the general US population and the study control group. The control group is made up of brothers and sisters (siblings) of participants who have volunteered to take part in the study. More than a third of the survivors (611 or 34%) reported having at least one thyroid abnormality, compared to about two percent of the control group.

Underactive thyroid. The most common problem, reported by 28 percent of the group, was an underactive thyroid, also known as hypothyroidism. Overall, the rate of hypothyroidism for survivors was 17 times the rate for the sibling controls. People who had been treated with high doses of radiation were most at risk along with girls and those who were over age 15 when they were diagnosed with Hodgkin's. Investigators estimated that, by 20 years after treatment, people whose radiation dose was in the highest category had a 50

percent chance of becoming hypothyroid.

Overactive thyroid (hyperthyroidism) was reported by five percent of the Hodgkin's survivors. Their rate was eight times the rate for controls. Those who received high doses of radiation were most at risk of hyperthyroidism.

Thyroid nodules. Thyroid nodules, or lumps in the thyroid gland, are usually not cancerous, but they may be. Both thyroid nodules and thyroid tumors are known to be associated with radiation to the neck and our study confirmed that association. In our study, we also found that the risk of getting thyroid nodules was greater for females than for males. Nine percent of the survivor group reported having a thyroid nodule. Their rate was 27 times that of the control group.

Thyroid cancer. Twenty cases of thyroid cancer were reported among the 1791 individuals treated for Hodgkin's disease in our study. Fortunately, all the cancers were of a type that responds well to treatment, similar to what has been found by other studies. The rate of thyroid cancer reported in this study was 18 times the rate for the general US population, but, even so, it occurred in only one percent of the participants. Because thyroid cancer is so rare this rate actually represents only a modest increase in risk.

If you were treated for Hodgkin's disease you are at increased risk for thyroid abnormalities. It is important to have your thyroid checked annually, or as often as advised by your healthcare provider, because thyroid problems tend to progress over time. It is also crucial to know your treatment history and to share it with your doctor. If treated promptly, thyroid problems don't have to be debilitating or life-threatening, but continuing follow-up care by a provider who knows your history is essential.

*"Abnormalities of the thyroid in survivors of Hodgkin's disease" (authors: C. Sklar et al.) will be published in September in **The Journal of Clinical Endocrinology and Metabolism.***

Understanding risk

News reports about newly-discovered health risks are an almost daily occurrence, and can be both frightening and confusing. Some people may respond with excessive caution and anxiety, others with a skeptical attitude that could cause them to ignore genuine risks to their well-being. Dr. Joe Neglia, one of the Long-Term Follow-Up Study investigators and a pediatric oncologist at the University of Minnesota, provides some guidelines below to help you make sense of the often conflicting reports in the news.

Often we hear of risks and it usually goes something like: “A new study has found that people who drink 10 or more cups of coffee per day (or whatever behavior the researchers are studying) have a 100 percent increased risk of heart disease (or diabetes, or whatever disease they are studying).” What, exactly, does a report like this mean? How can a person interpret and use this kind of information? Certainly a 100 percent increase sounds impressive, but that number does not tell the whole tale.

To arrive at a conclusion like this, researchers have usually asked many questions of a large number of people; some have the disease they are studying and some don't have the disease. Take the make-believe “coffee study” just mentioned. When they asked people about their coffee consumption the researchers found that 20 out of 100 people with the disease drank a lot of coffee, compared to only 10 out of 100 people without the disease. Thus, in this study *100 percent more* people with the disease drank 10 or more cups of coffee than did people without the disease.

Another way to say this is that persons with the disease were *twice as likely* to be heavy coffee drinkers as those without it. Would you rather have a 100 percent increase or twice the increase in risk? They actually mean the same. More importantly, neither really tells how likely you are to get something. A 100 percent increase in risk DOES NOT mean that the likelihood of getting the problem is 100 percent.

Here is another example. The likelihood of any child being diagnosed with leukemia is about one in 2000. A doubling of risk, or a 100 percent increase, would lead to a risk of approximately two in 2000, still quite unlikely. On page three of this newsletter the authors have noted that patients who had Hodgkin's disease were 18 times more likely to develop thyroid cancer than the general population. Important data, and if you had Hodgkin's disease it is something you should discuss with your doctor. However, the risk of thyroid

cancer in the general population is low and, even with this risk, almost 99 percent of former Hodgkin's patients did not develop thyroid cancer.

So, should you change your life based on reports about risk factors? First, try to understand what your real risk is, considering your health history, your habits, and the overall likelihood of a particular problem occurring. Then look at the change you are thinking about making, and what the consequences of such a change would be. If it is quitting smoking cigarettes or cutting back on excess alcohol consumption, the answer is self-evident. Quit! Cut back! Other things, like a major change in diet, might be more difficult. You need to weigh all the benefits against the risks.

Finally, risks and benefits always have to be interpreted with knowledge of your background likelihood of a condition or event. Here is one last example: Buying 100 lottery tickets will increase your odds of winning 100 times, but you'll only go from one in 64 million to 100 in 64 million and, at the end of the day, be out 100 dollars (unless you're *really* lucky!)

Lifestyle changes and regular medical care can reduce risk and should be part of everyone's health practices. Your healthcare provider can help you make sense out of new findings. He or she can also help you make wise lifestyle choices and changes, taking into account the complete picture of your health history and future.

Our mailing address is:

*Long-Term Follow-Up Study
1300 S. Second Street, Suite 300
Minneapolis, MN 55454*

Toll-free phone number:

1-800-775-2167

email:

ccss@epi.umn.edu

website:

www.cancer.umn.edu/ltfu