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- University of Minnesota
- The Denver Children’s Hospital
- Children’s Hospital of Pittsburgh
- Children’s Hospital at Stanford
- Dana-Farber Cancer Institute
- Emory University
- 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

<b>Inside</b>	
<b>Study update: health care access</b>	<b>2</b>
<b>Finding community health care</b>	<b>2</b>
<b>Study social worker: Sally Wiard</b>	<b>2</b>
<b>Sally’s health insurance checklist</b>	<b>3</b>
<b>Recommended resources</b>	<b>4</b>
<b>Young adult camping conference</b>	<b>4</b>

## From the editor

By now, many of you have received the “Follow-Up 2” questionnaire, our third comprehensive survey of Long-Term Follow-Up Study participants. If you haven’t received yours yet, you will be seeing it sometime this spring or summer. We hope to complete the mailing of questionnaires to all participants (except the sibling group) by early October.

Many of the sections of the Follow-Up 2 will look familiar to you. As usual, we are asking you to update us on medical care you have received in the past two years, as well as on your use of medications, your pregnancies, and your family history. However, a large part of the questionnaire is devoted to a new subject - your “quality of life.”

**Quality of life** is a phrase that is sometimes used to describe a range of things that can contribute to or take away from our satisfaction with our lives. Another word for quality of life is well-being. Our physical and emotional energy levels, our ability to meet life challenges and accomplish our goals, our feelings about ourselves and our relationships, and our spirituality are all parts of our sense of well-being, or quality of life.

Experiencing a condition such as cancer or a similar serious illness could certainly have an impact on a person’s quality of life. We are asking you to help us learn about the kinds of effects you may have experienced, both what has caused you difficulty and what has made a positive contribution to your well-being. As you complete the Follow-Up 2 survey, please give careful consideration to the quality of life questions. This is a fresh area of research where, once again, LTFU participants have an opportunity to help make medical history, and to provide information that may increase the quality of life for all survivors.

**Health Insurance.** This edition of the LTFU newsletter focuses on health insurance and access to health care - definitely a topic that affects quality of life! Obtaining and maintaining adequate health care coverage can be a challenge for everyone, especially in uncertain economic times. People who have experienced a serious illness may need an extra dose of persistence in dealing with the health care and insurance systems.

LTFU researchers recently completed a study of health care access among our young adult participants. We report their findings on page 2. Also in this issue, we explore ways to help you get the health care you need.

**New newsletter design.** We hope you enjoy the new look of our newsletter. We’re happy to be communicating with you in full color from now on!

## Study update: Health care access

LTFU researchers led by Dr. Kevin Oeffinger, recently completed a study about health care visits of our adult participants. The study showed that as more time passes from diagnosis, fewer and fewer people have medical check-ups that are related to their previous cancer or similar illness. Less than half (42 percent) had had a cancer-related follow-up visit, i.e., a visit specifically related to their cancer or treatment. People also tended to have fewer general physical exams as they got older and further out from their cancer diagnosis. This was true even for people who had been treated with therapies that are associated with increased risk of heart disease or breast cancer. The researchers also found that men were less likely than women to report a health care visit.



Dr. Kevin Oeffinger

The researchers on this study concluded that cancer centers and primary care doctors need to develop effective methods of communicating with long-term survivors to ensure they get the best possible care, taking into account their risk for late effects from treatment of their childhood illness.

Dr. Oeffinger is a professor of Family Practice at the University of Texas Southwestern Medical Center at Dallas and an investigator with the LTFU. His research paper, "Health Care of Young Adult Survivors of Childhood Cancer" will be published soon in the journal *Annals of Family Medicine*.

## Finding health care in your community

As a person who has had childhood cancer or a similar serious illness, it is important for you to have regular medical check-ups, particularly since some of the treatments you received may increase your risk for health problems as you get older. To find out if you are getting adequate care, ask yourself the following questions:

1. Do I know my cancer diagnosis and specific treatment I received?
2. Do I know about the health problems that can occur after this treatment?
3. Have I shared this information with my primary care doctor?
4. Have I asked my cancer doctor to inform my primary care doctor about the details of my history and the health risks specifically associated with my childhood illness and its treatment?

5. Does my primary care doctor check periodically for health problems specifically related to my childhood illness?
6. Does my doctor advise me about things I should do or not do to keep healthy because of my childhood illness?

With these questions in mind, there are several things you can do to make sure you are getting the best possible care for your needs:

**Choose a primary care doctor in your community.** The best primary care doctors for adults are usually family practice doctors or internists. People graduating from pediatric care often request a referral to a physician who has experience taking care of childhood cancer survivors. The chances of finding a doctor with this experience are low because of the rarity of serious illnesses like cancer in children. Instead, you should look for a doctor who is thorough, well-trained, and a good listener. Ask friends and family members to help you identify doctors with these qualities who are practicing in your area. Make an appointment for a general check-up and discuss your past medical history and health risks and screening with your doctor during this visit when you are not acutely ill.

**Organize a medical team to provide your local care.** Get advice from your former cancer doctor and your primary care doctor about who should be on your medical team. Your team should always include your primary care doctor and a dentist. Depending on your situation, you may also need to include

***continued on page 4***

## Insurance tips from LTFU social worker Sally Wiard

Sally Wiard is the clinical social worker for the After Completion of Therapy (ACT) clinic at St. Jude Children's Research Hospital in Memphis, Tennessee. She received her training at the University of Missouri-Columbia. Sally has worked exclusively with cancer patients since 1986. She has been at St. Jude for the past five years. One of the things she likes about her work is the opportunity to form long-term relationships with her clients. She says, "It is very rewarding helping people become more independent and regain their autonomy." Obtaining insurance or other means of paying for health care can be a special challenge for people who have had childhood cancer or a similar serious illness. Social workers can be a great resource in this area. If you need help, Sally recommends checking with a social worker at your local hospital or clinic. She emphasizes that "there are people who will help you out there. If you haven't found that person, don't give up. Always start with somebody you trust. Ask for help." Sally's checklist for obtaining insurance coverage is on the facing page.



Sally Wiard

# Sally's checklist for obtaining health care coverage

## Define your current health care needs. Ask yourself:

- Do I mainly need a doctor for **general check-ups**?
- Do I have **chronic** health problems that require frequent doctor visits?
- Do I have problems that need periodic monitoring by **specialists**?
- Am I on expensive **prescription** medications?
- Do I require **prosthetic** or **rehab** services?

## Explore all resources for health care coverage:

- Private insurance coverage through a **parent's** or a **spouse's** policy
- Health insurance coverage offered by your **college** or **employer**
- State or federal **public assistance** programs
- Discounted or **free** health care through **health department** clinics or **church-based** programs
- Indigent **prescription** programs

## If you are insured, get the facts about your policy.

- What **services** are covered?
- Does your plan offer a **discounted prescription** program?
- Are **referrals** to specialists controlled through a primary care physician?
- Are limitations set on **pre-existing** medical conditions?
- Is coverage in effect only while the patient is a **full-time student**?
- Does coverage **expire** at certain age?

## Ask for help in understanding current resources and locating new ones.

- Ask **family** members, **friends**, **hospital** or **clinic** insurance managers, and insurance representatives to help explain unclear details about insurance benefits.
- Call a clinic or hospital **social worker** to ask for help in finding state or community health care resources.
- Check out services offered by national **nonprofit** organizations (example, Lions Club for ocular prostheses).
- Be proactive in obtaining and maintaining health care coverage.
- Contact your **state insurance office** to get a list of insurance providers in your state.
- Call your **county** department of human services to find out if you qualify for health care through state or federal programs for people with **low income** or **disability**.
- Begin applications.
- Avoid lapses in coverage. Plan for **transitions** in health care coverage that occur with **college graduation** or **job changes**.
- Be aware of the **laws** that help you keep insurance benefits:
  - COBRA** (Consolidated Omnibus Budget Reconciliation Act) requires employers or larger businesses to make insurance benefits available for a limited time to employees (and their dependents) who are fired or laid off.
  - HIPAA** (Health Insurance Portability and Accountability Act of 1996) allows people with pre-existing conditions to keep comprehensive insurance coverage when they are changing insurance plans or jobs.
- Certain conditions apply that may limit the help available to you under HIPAA. Contact your social worker, insurance provider, or state insurance department with questions.

## Be persistent when meeting obstacles. Try not to get overwhelmed.

- Follow through** with applications.
- Appeal** denials with letters of support from your doctor.
- Begin **new applications**.
- Contact ombudsman programs of groups like **Candlelighters** and the **National Coalition of Cancer Survivors** for more information about health care resources.
- Don't give up!

**continued from page 2**

other medical specialists. For example, if you have a chronic seizure disorder you may need a neurologist. Sometimes

if you can be referred to a medical specialist or facility that offers discounted rates or payment plans for individuals who are uninsured.

**LTFU study participant Amorette Bleu-Dye is glad she has her treatment records!**



Amorette

When she needed dental work, Amorette asked the LTFU study to help her obtain a copy of her cancer treatment records. She recently wrote us:

"I had the first of my dental procedures last week and I must say it went like a dream. . . . Without the records . . . I might not have been able to go through with the necessary repairs. Proof of my history seems to have made an enormous difference in my care. . . .

"I was incredibly touched to find that I could benefit from the study while participating, in addition to my case being of later benefit to others. Thank you so much."

As a survivor of serious illness you have already overcome many obstacles. The process of obtaining, and paying for, health care can sometimes be discouraging. It is worth the effort,

other health care providers, such as a physical therapist, a prosthetist, or a psychologist are important for your continued health. Your primary care doctor can help you select these individuals and give you referrals for their services.

however. As one survivor put it, "I ask myself, is it as bad as cancer? Nope, I can handle it!" For more ideas, be sure to check out the resources listed below.

**Share your medical records with all the members of your medical team.**

If possible, ask the doctor who treated you for your childhood illness to write a letter summarizing your diagnosis and treatment, future health risks, and recommended screening tests. Ask the hospital or doctor's office to send copies of your treatment records to all your new doctors. Keep a copy of the letter and important sections of your pediatric records in a personal medical file. Be sure that every new health care provider you see is aware of your medical history and any special health risks you may have because of your treatment. Provide contact numbers of the doctors who treated your childhood illness. If you need help in obtaining medical records of your treatment, you can call the LTFU study toll-free number. LTFU staff can also provide your doctors with more detailed medical information about the types of health risks and recommended screening tests related to your childhood illness.

## Recommended resources

**The National Coalition of Cancer Survivors** is a patient-led advocacy organization for cancer survivors. Their booklet *A Cancer Survivor's Almanac* lists hundreds of organizations and agencies that offer help regarding specific cancer-related issues, including finding affordable health care. The booklet is available at their website, [www.cansearch.org](http://www.cansearch.org). Their phone number is (877) 622-7937.

**HIPAA.** Information about the Health Insurance Portability and Accountability Act of 1996, which helps people with pre-existing health conditions get and keep health insurance, is available on the website of the U.S. Department of Health and Human Services at:

<http://cms.hhs.gov/hipaa/hipaa1/content/cons.asp>

**State Insurance Commissioners.** Contact information for insurance commissioners of each state is also listed on the HIPAA site at:

<http://cms.hhs.gov/hipaa/hipaa1/content/contacts.asp#ContactCMS>

**Explore all resources for paying for health care.** Health care is expensive and people who have had a serious illness often face many hurdles when trying to obtain adequate health care coverage. However, you may still be able to get insurance, even with your health history. Milestones of five, seven, and ten years from the end of treatment seem to be important to insurers. Ask your doctor to write a letter to the insurance company documenting your long-term remission.

## Camping conference

Join other childhood cancer survivors at Camp Mak-A-Dream in Gold Creek, Montana August 15-19, 2003, for the first annual Young Adult Survivors Conference, a camp experience that provides young adults in their 20s and 30s who have had cancer with the skills to be advocates for themselves, others, community, and society. The conference is free to participants and there is room for 50 campers. Please contact Camp Mak-A-Dream for application materials and additional information. Phone: (406) 549-5987; email: [camp@montana.com](mailto:camp@montana.com); website: [www.campdream.org](http://www.campdream.org).

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