

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.stjude.org/ltfu).
- Click the link on the left side of the web page labeled **Contact Info Update Form**.
- Update address and telephone number. Also give an e-mail address, if you have one.



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For a list of participating centers,

see our website:

www.stjude.org/ltfu

Spotlight on Siblings

Spring
2009

“Without the siblings, we could not conduct this Study.” This is how Dr. Greg Armstrong explains the importance of siblings to our research. To learn why siblings are central to our success, turn to page 3 for our interview with Dr. Armstrong, LTFU Study project director.

Siblings are survivors too. In 1981 when the Rome family found out that Jessie (then 2) had cancer, doctors were focused almost entirely on curing the cancer and the needs of the seriously ill child.

In the past 30 years, we have seen a changing culture in cancer care. We now know that serious illness has a profound and lasting effect on the entire family, not just the person who undergoes treatment. We also know that siblings need support to help them address their own fears and concerns.

Notes from Survivors (page 4) shows how the Rome family provided social and emotional support for Jessie's older sister, Emily, while making sure that Jessie received the care she needed.

Risk-based care and screenings. Most survivors in the Study do a good job of seeing doctors regularly. But they do not always receive recommended screenings based on earlier illness and treatment. See the Study Update (page 2) for details. In her comments, Dr. Hudson tells how survivors can make sure they get the screening tests they need.

—Margaret Carbaugh, Managing Editor

You Can Still Complete Questionnaires

Whether you are a survivor or a sibling, we thank you for your continued contribution to the LTFU Study. Without you, we could not conduct the studies published in this newsletter. Thanks for staying with us over the years and continuing to share valuable information about your lives and experiences.

If you have not completed the most recent Study questionnaire, you may do so in one of the following ways:

- Complete the paper version and mail back to us.
- Complete over the telephone with our survey staff or over the internet. We can help you either way.

Contact the survey center if you have questions or need help:

- Telephone: 800.775.2167 or 901.595.6600
- E-mail: ltfu@stjude.org

Early spring at
the LTFU Study
coordinating
center, Memphis



Study Update

Risk-Based Care and Screening among Survivors

Adults who had cancer or other serious childhood illness do a good job of seeing their doctors regularly, but their care is not always focused on the risks they face. This is a problem, says Dr. Paul Nathan of the Hospital for Sick Children in Toronto. He recently led a research study to find out whether survivors receive medical care focused on late effects. Some results reported here reflect additional data from the LTFU Study.

If you received certain treatments during childhood, doctors should monitor your health more often now that you're an adult. Here's what we found out in our study:

- Most of the 8,500 participants (89%) had some form of medical care in the past 2 years.
- Fewer than a third had care focused on their cancer.
- Fewer than 20% received advice about how to reduce their risks or to screen for late effects.
- 809 had radiation to the abdominal area. Yet only 92 (11%) had colon cancer screenings every 5 years.
- Fewer than a third of the women who had radiation to the chest had recommended annual breast cancer screenings.
- Nearly 2,000 survivors in this study had treatments that increased the risk of heart disease. Yet only 511 (28%) had recommended tests to check for heart muscle function.

Most survivors don't see late effects specialists. So it's important that they learn about health screening tests and share what they learn with their doctors.

What results tell us. Many Study participants do not get screening tests for late effects, even though they have specific risks linked to previous illness or treatment. Also, they are not following more general screening guidelines, for example, yearly Pap smears for women.

Screenings were conducted more often at cancer centers where health care providers are familiar with cancer-related health risks. But few participants in this study were seen at a cancer center.

These results tell us that we need to do a better job of teaching survivors about treatment-related health risks and the importance of general cancer screenings. Only then can they speak up for the type of care and screening tests they need.

Most survivors don't see a specialist in the late effects of cancer. So it's important that they know about the details of past treatment and health screening tests they should have. It's even more important that they share this information with any doctor they see.

To find out more. Details were published in the *Journal of Clinical Oncology* (Sept. 20, 2008).



Dr. Paul Nathan

Comments by Dr. Melissa Hudson

Make Sure You Get the Health Screening Tests You Need

We like to catch signs of potential late effects early on, when efforts to help you can do the most good. For example, your doctor may pick up a small breast cancer on a mammogram. If it's not found until it spreads to the lymph nodes, the treatment and outcomes will be very different.

Did you know that you have a part to play in making sure such outcomes are positive? You can help us by making sure that you get the health screenings you need.

You are more likely to have recommended screening tests if you go to cancer centers or clinics where doctors specialize in the late effects of treatment.

If you don't, you need to help your family doctor or primary care doctor understand the types of screening tests you need. This means you will need to know details of your diagnosis and specific treatments, as well as the specific risk that comes with the treatments.

In earlier newsletters, I have explained the facts you need to know to understand your health risks. For a summary, see the box on the next page.

You can help us do our job of keeping you healthy.

To find this information, you may need to contact the institution where you received treatment and ask to have records sent to you.

With this information, you and your doctor can find out what health screening tests are recommended, based on the treatments you received.



Dr. Melissa Hudson

An Interview with Dr. Greg Armstrong, LTFU Study Project Director

We Couldn't Do the Study Without the Siblings

We are often asked why it's important for siblings to take part in the LTFU Study even though they did not have cancer or other serious childhood illness. In this interview, Dr. Greg Armstrong explains the role of the 4,000 siblings in the comparison group. He also points to future directions for the Study.



Why are siblings important to the LTFU Study?

We couldn't do the study without them. It's that simple.

It is important to know how specific health outcomes for survivors compare to those of adults who did not have cancer during childhood. We could compare survivors to the U.S. population for things such as height and weight. This is not always the most correct approach since many factors can influence height and weight. Examples include genetics, family income, and childhood environment.

Having information on siblings from the LTFU Study allows us to draw conclusions that are more precise for childhood cancer survivors. The siblings are similar to the survivors in almost every way except one. They did not receive treatment for cancer or other serious illness during childhood.

If we see health problems in survivors that do not show up in siblings, we have evidence that they may be due to late effects of treatment during childhood.

Do you compare survivors to their own sibling?

No, we do not. We compare the two groups as a whole.

Because we do not compare siblings to their brothers or sisters, the sibling remains a valuable part of the Study even if the brother or sister drops out.

Why is the study so long?

Many late effects do not show up until years after treatment ends. By looking at participants 20 and 30 years past diagnosis, we may identify rates and risk factors for health problems such as late-occurring second cancers. We can also look at how lifestyle choices such as smoking and sun tanning affect health risk.

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What's in the future for the Study?

We plan to look more at family history. We also plan research studies to learn more about the siblings' own experience.

You may have read about our plans to add 20,000 participants to the LTFU Study. Like the survivors currently in the Study, they received treatment for a serious illness during childhood. But they received treatment after 1986. By comparing their health status with the outcomes for those who received treatment earlier, we can see how changes in medical care affect the health of future survivors.

To learn more, go to a resource like the Children's Oncology Group *Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*.

You can find the guidelines at:

www-survivorshipguidelines.org

Also, see the following features in the LTFU Study newsletter:

- Find a Doctor Who Understands Spring 2006
- Dr. Hudson's Comments Fall 2006

You can find these and other issues of the LTFU Study newsletter on-line at:

www.stjude.org/ltfu

To Understand Risk, You Need to Know

About Your Original Diagnosis

- Date of diagnosis
- Type of cancer or other childhood illness
- The part(s) of your body affected

About Your Treatment

- If you had surgery, what type of procedures?
- If you received radiation, when was it, where was it (part of body), and what doses did you receive?
- If you had chemotherapy, what specific drugs did you receive?
 - If you received anthracyclines and/or alkylating agents, what was the total dose?
 - If you received methotrexate, were any of the treatments considered "high dose" ?
- If you received a bone marrow transplant or stem cell transplant, when was it?

Notes from Survivors

A Sibling Reflects: What Mattered Most During Her Sister's Treatment

It's been 30 years since doctors diagnosed vague, flu-like symptoms as cancer in Jessie Rome. Today, Emily Rome Welter recalls what it felt like to be 5½ and worried that her 2-year-old sister might not live.

As she reflects on life “then,” what matters is not that she felt scared or lonely or that she worried about death. What matters is the fact that her parents helped her cope with her feelings. And, despite having to focus on Jessie, they made sure that Emily's childhood was as normal as possible.

To treat her acute lymphoblastic leukemia (ALL), Jessie had chemotherapy and radiation at the University of Minnesota Children's Hospital. Emily and her dad stayed in their home town (Mankata) so he could try to work and so that daily life could go on for Emily much as it did before.

Of their weekend visits, Emily recalls seeing a bright new playground at the Ronald McDonald House in downtown Minneapolis. She next noticed that there wasn't a single child to play on it because they were all too ill. “I knew that everyone was under a lot of stress, so I didn't complain *too much*,” she says.

At 5½ Emily was at the age when kids begin to have lots of questions about death. “That must have been hard on my parents,” she says. As a family, they attended the funeral of a kid on Jessie's unit. And, their mom once insisted that they all talk to a psychologist. After a few visits, he said they were

copied pretty well.

Back home, Emily's parents talked to teachers to make sure that her school progress wasn't affected. In addition, they had someone supervise after-school hours and prepare dinner. Having a neighborhood “grandma” around helped reassure Emily that someone was there for her.

After 8 weeks of treatment, Jessie came home. In usual kid fashion, Emily began to wonder how much longer it would take her to get well. “I was also mad that other kids couldn't come within a stone's throw of our house because Jessie might catch some bug from them.”

Jessie continued with out-patient therapy until she was 10. Her cancer has not recurred.



Emily, now 35, reflects on the lasting effect of growing up with a sister who had cancer. “Our family was always very close,” she says. “We have stayed close because we learned to face problems and talk things through.” Emily and Jessie learned another lesson from their parents and their quick response to Jessie's symptoms: Don't mess around when it comes to medical issues.

In the past two years alone, Jessie has had more than 20 medical visits. Most were due to a nerve condition causing pain in her neck and face, possibly the result of radiation therapy. To help doctors come up with a treatment plan, Jessie has given them copies of her medical records and makes sure they know about her health history.

Because two family members have had cancer (Jessie and her father), Emily thinks about what health issues she and her children might one day face. “There's not much I can do other than pay attention and try to stay healthy,” she says.

Special Note to Sibling Survivors

Yes, you are a survivor too!

As you read Emily's story, keep this in mind: Not all parents were as tuned in to the needs of siblings as was the Rome family. This was especially true 20 or 30 years ago, when many survivors in the LTFU Study received treatment.

Today we know that siblings have their own unique needs and experiences related to their brother or sister's illness. Many hospitals now offer programs just for siblings. In addition, groups such as SuperSibs offer ongoing support for the brothers and sisters of children who had cancer.

Resources: To explore what's being offered to sibling survivors today, visit the SuperSibs website:

www.supersibs.org

To read more about the experiences of being a sibling survivor, see *Childhood Cancer Survivors: A Practical Guide to Your Future* (pages 56 to 59).



Jessie has found her way to “give back” by working as a school counselor with elementary-age children. Emily is a partner in a law firm that handles large and complex business cases. She volunteered at a Ronald McDonald House while she was in college. Emily (far left) with Jessie and her sons Jacob and Matthew.