

# A BRIEF UPDATE

From the Long-Term Follow-Up Study

January 2015

<http://ltfu.stjude.org>

## Topic: REDUCED TREATMENT SIDE EFFECTS for children diagnosed with low-risk leukemia

**Why** is this topic important for survivors?

Thanks in part to survivors' participation in research, most children who are treated today for low-risk acute lymphoblastic leukemia (ALL), the most common childhood cancer, no longer receive brain radiation and they receive reduced amounts of chemotherapy compared to children treated in the past. Children in the low-risk group are diagnosed at age 1 to 9 years and have a lower white blood cell count than children in the high-risk group.

**Who and What** we studied:

To find out more about the likelihood of delayed side effects for children who are currently being treated for low-risk ALL, we looked at questionnaire responses from LTFU Study participants who were diagnosed between 1970 and 1986 and received treatments that are similar to those used today.

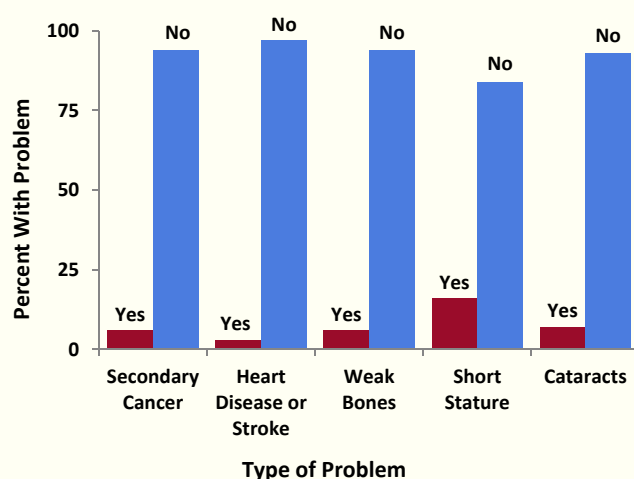
The study included 556 ALL survivors and 2,232 siblings. Survivors were an average of 23 years from diagnosis.

**What** we found:

- Survivors in this study were at very low risk of death from any cause. Compared to members of the general population, there was no significant difference in risk of death from a second cancer, heart disease, or lung disease.
- Just 2 percent of the study group (12 patients) died of a recurrence. This suggests that a reduction in therapy did not increase the risk of recurrence.
- Only 1 percent of survivors developed a secondary cancer.
- Survivors were as likely as siblings to report good physical and mental health, to marry, live independently, graduate from college, and have health insurance.

- Survivors were at very low risk of developing a new chronic health problem. They were not much more likely than siblings to develop chronic health problems.
- Compared to siblings, survivors were at increased risk of osteoporosis or osteopenia (weak/brittle bones), growth hormone deficiency and short stature, and cataracts. However, the number of survivors who had these problems was very small (*See figure below.*)

Few survivors of low-risk ALL reported chronic health problems



**In summary:**

- ✓ ALL survivors who received treatments similar to those that are used for current patients are at a low risk of death or major side effects.
- ✓ Information provided by LTFU Study participants reassures us that current low-risk ALL patients will also experience a low risk of mortality and side effects.
- ✓ Since these survivors are at low risk of developing life-threatening conditions, it's likely they can be adequately cared for by a primary care physician who is well informed about the details of their treatment and about the health screenings recommended for these survivors.

**Reference:** Risk of late effects of treatment in children newly diagnosed with standard-risk acute lymphoblastic leukaemia: a report from the Childhood Cancer Survivor Study cohort. Essig S, Li Q, Chen Y, Hitzler J, Leisenring W, Greenberg M, Sklar C, Hudson MM, Armstrong GT, Krull KR, Neglia JP, Oeffinger KC, Robison LL, Kuehni CE, Yasui Y, Nathan PC. *Lancet Oncol.* 2014 Jul; 15: 841-51.

## Survivorship Research Benefits Current and Future Survivors

We're glad that participants in the LTFU Study have made a choice to participate in survivorship research. The information you provide on the study questionnaires helps make research like that reported in this newsletter possible. Thank you, participants. We appreciate your partnership in the the LTFU Study.

Our hope is to help you become empowered survivors who take control of their own health. Empowered survivors take actions to manage their health – everything from informing their doctors about their treatment history to practicing healthy habits like being physically active and maintaining a healthy weight to joining together with other survivors for support and encouragement. Evidence suggests that people who take an active role in managing their health tend to enjoy better health and have greater satisfaction with their healthcare.

### ***The findings reported for this study of ALL survivors are very favorable.***

They show that ALL survivors who received treatments similar to current treatments for low-risk ALL are at a low risk of death or major side effects and are leading healthy lives. The authors suggest that such survivors might not need to be followed at a specialized survivorship clinic but could likely receive much of their care from their local primary care doctor instead.

Being cared for by a well-informed primary care doctor may help remove some anxiety for survivors of low-risk ALL and others who are at low risk of delayed treatment side effects. It might also potentially reduce some costs associated with travel to a survivorship clinic.

This arrangement can only work well if survivors share the complete details of their treatment history with their primary care doctors. It's important for all survivors to have a detailed summary of their treatment, regardless of where they receive their routine and follow-up care. If you don't have a treatment summary, request one from the center where you were treated for your childhood illness.

### ***COG Survivorship Guidelines***

*COG – The Children's Oncology Group – is the world's largest pediatric research organization. COG provides risk-based screening recommendations for survivors of pediatric cancer online at:*

<http://www.survivorshipguidelines.org>

***Please share this information with all your healthcare providers!***

While the participants in this study were found to be at low risk of health problems, the authors caution that the study was not designed to detect developing conditions that have not yet resulted in illness. This is one reason why it's so important even for healthy survivors to make sure they have the recommended health screenings based on their specific treatment risks.

### ***Diana Merino: Empowered Survivor***

Diana is a survivor of Hodgkin lymphoma who later developed a secondary cancer. "That's why I am so aware of the need for continued check ups and screening – but beyond that to listen to your own body and be aware of what's going on with it," she says.

"I wouldn't dream of going to my primary care physician without a detailed treatment summary because I couldn't possibly remember all the drugs and doses I received. My doctor needs this detailed information to know the possible health risks I face based on my cancer treatment and what health screenings I need."



### ***Online Resources***

**The Association of Cancer Online Resources (ACOR)** is a collection of online communities that offer support for cancer patients and survivors. Find them at:

[www.acor.org](http://www.acor.org)

**The Patient Empowerment Network** is an online community that partners with major medical centers and foundations to help patients and families who are dealing with cancer and serious, life-long chronic conditions. This organization offers a collection of resources for patient self-efficacy (as well as some resources for medical professionals) at the following web address:

[www.powerfulpatients.org](http://www.powerfulpatients.org)