

LTFU

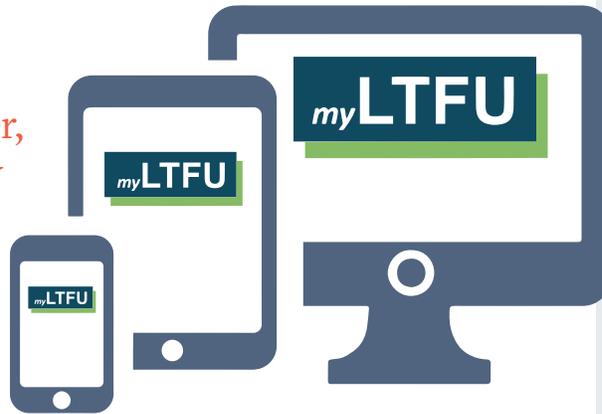
Long-Term Follow-Up Study

# Update

Autumn 2019

## myLTFU: Your new personal study portal

Whether you use a smartphone, tablet, or desktop computer, myLTFU offers easy access to surveys, resources, and important study updates.



myLTFU offers a simple, secure way for LTFU participants to complete follow-up surveys. For example, you can start your survey on your laptop, continue it on your phone while you wait for the bus, and finish it at work during lunch using your desktop computer.

In the coming months, myLTFU will also let you:

- See how some of your survey answers compare with other participants'
- Access resources chosen for you based on your original treatment information
- Receive updates and messages from the LTFU Study team
- Learn about opportunities to participate in additional studies

Invitations (shown below) to access the new follow-up survey with

myLTFU have been mailed to every study participant. Your personal key code is printed inside the invitation, with instructions on how to activate your portal.

If you didn't receive an invitation, or if it's lost, just let us know, and

we'll send you the login information you need to access myLTFU. You can call us toll-free at 800-775-2167 or email us at [ltfu@stjude.org](mailto:ltfu@stjude.org).

**View myLTFU activation tips on page 2.**



### A NOTE FROM US

Early reviews of myLTFU, our new study portal, have been very positive! Our Participant Advisory Council provided some early testing and responded enthusiastically. You can see some of their comments on page 2 (as well as some of their suggestions that helped shape the new survey). We're excited to be rolling it out to everyone, and we look forward to your feedback!

In a study like ours, with more than 24,000 participants across the US (and some around the globe), it can be challenging to feel connected with each other. To help address this, we recently made our first video. I greatly enjoyed the opportunity to "talk" to all of you who make the LTFU Study possible.



Watch Dr. Armstrong's video update about the new follow-up survey, myLTFU, and the importance of survivorship research. [ltfu.stjude.org/myltfu](http://ltfu.stjude.org/myltfu)

This video (and more to come), the new myLTFU, and the Participant Advisory Council are some of the ways we are working to keep you involved and informed. And we're always glad to hear from you! You can call us toll-free at 800-775-2167 or email us at [LTFU@stjude.org](mailto:ltfu@stjude.org).

Thank you for being our research partner.

Greg Armstrong, MD  
Principal investigator

# Tips for activating and using myLTFU

Activate myLTFU here!

URL: [ltfu.stjude.org/myLTFU](http://ltfu.stjude.org/myLTFU)  
Key code:

**Step 1:** Activate myLTFU by visiting [ltfu.stjude.org/myLTFU](http://ltfu.stjude.org/myLTFU). Enter your date of

birth and the key code we sent you, then check “I’m not a robot,” and click “Activate.”

**Step 2:** Now you can log in to the LTFU Study portal. Enter your email address and create a new password. You will use this email and password to log in to myLTFU in the future.

If you’d prefer to use a four-digit PIN (personal identification number) instead, click “Login from this browser using a PIN from now on,” and create your PIN. (A PIN is not required, but some people find it more convenient.)



## myLTFU feedback

“An amazing resource. Kudos!”

“The functionality and ease of use are just great!”

“I like that all the resources are accessible in one area.”

“It’s easy to navigate. I look forward to what is yet to come.”

“To have all those articles in one place, without having to do individual Google searches for them, is very helpful.”

## We hear you! Participant input helps shape LTFU Study

LTFU’s Participant Advisory Council (PAC) is helping the research team understand what it’s like to be part of the study—what works and what might make it better.

During the planning stages of the current survey, 72 PAC members responded to an online questionnaire (73% response rate) requesting their input. Here are some examples of what we heard and how we responded:



**“I’d like to be able to complete my survey in several sessions, saving my answers so I can come back later.”** This capability was already

built into LTFU’s online surveys, but we learned that many people just weren’t aware of it. We’re making an extra effort to let everyone know that your answers are stored when you log back in.



**“A longer survey deserves more incentives.”**

Many PAC members felt that surveys that are more time-consuming should offer extra incentives in addition to the usual \$10 gift card. The current survey is a comprehensive update of participants’ health information. With that in mind, we are organizing, for a limited time, monthly drawings for a smart watch to promote engagement in the new myLTFU portal.



**“Incentives don’t matter to me, I’d rather the money went to research.”** Other

participants indicated that they would prefer to donate their incentive to support LTFU research. We appreciated their thoughtful suggestions, and this option is now available.



**“I’m just not into technology, thanks.”**

Along with enthusiasm for the new mobile-friendly portal, we also heard that it is important to continue offering our traditional survey formats. Rest assured, we are not taking away any survey options. Participants who prefer the print version or who want to complete their survey on the phone with a trained interviewer can still use those methods. Print versions will be mailed out after the online survey has been completely launched.

**“More knowledge = More power.”** This theme

emerged loud and clear when we analyzed PAC members’ comments. Study participants want to know how they can protect their health and are committed to helping advance this knowledge. Thanks to our PAC, “More knowledge = More power” became the theme for this survey’s outreach campaign.

Thank you to everyone who shared your ideas and opinions. We value your time and your insights.

We are still welcoming new PAC members. We reach out to PAC members on an as-needed basis. There’s no time commitment. To join, please email us at [ltfu@stjude.org](mailto:ltfu@stjude.org).



# Sleep, emotional distress, and physical health during survivorship

More survivors reported poor sleep and emotional distress than their siblings, and were more likely to use medication or supplements to address their sleep issues. “Sleep is something we can improve,” says the study’s lead researcher.

Studying LTFU data of more than 4,000 survivors and 380 of their siblings, researchers found higher rates of sleep problems and snoring among survivors. Survivors who reported that their emotional distress, such as anxiety or depression, increased over time were also more likely to report poor sleep.

The study defined poor sleep as taking more than 30 minutes to fall asleep three or more times a week, or sleeping for less than 85% of the time spent in bed. Although this study doesn’t prove that sleep causes emotional distress, the two are closely related, which may mean that improving sleep could have an impact

on emotional distress.

The study also found that more survivors than siblings were using medication, supplements, alcohol (though it actually makes sleep more difficult), and warm milk (for which there is no scientific evidence) to induce sleep.

## Effective treatments are available

“Sleep is something we can improve,” says Lauren Daniel, PhD, Rutgers University, the lead author of the study. “Many survivors continue to experience sleep problems after their treatment ends. And, as in the general population, sleep challenges can increase as one ages. I want survivors to know that effective treatments are available.”

Sleep medications, whether over the counter or prescribed, only treat the symptoms of poor sleep, not the cause, so they are not an effective long-term solution. They can also be habit forming. “Cognitive behavioral therapy is the gold standard for treating insomnia,” says Dr. Daniel. “It helps improve sleep habits and reduces the stress of not being able to sleep. It works really well, and the effects can be long-lasting.”

## Speak with your provider

Dr. Daniel hopes her study “helps providers be more aware of who is using sleep medication and to refer those patients to more effective treatments.”

Survivors who have trouble falling asleep, staying asleep, or who regularly snore should talk to their primary health providers, who can help assess the issue, recommend evidence-based treatment options, or make a referral for an overnight sleep study.



LTFU participants contributions to research offer a unique perspective, helping us understand quality of life issues that we know continue over time,” says Lauren Daniel, PhD, lead author of the study.

## A good night’s sleep It’s not just counting sheep

Having trouble sleeping? Healthy sleep habits can make a big difference in how you feel. Here are some suggestions:

- Set a sleep schedule so you go to bed and wake up at the same time every day, even on weekends.
- Exercise daily. Even light activity, any time of day, can help.
- Skip alcohol, cigarettes, and caffeine in the evening, all of which can disrupt sleep.
- Avoid eating large or spicy meals within two to three hours of bedtime. Have a light snack 45 minutes before bed if you’re hungry.
- Turn off the TV, computer, and phone an hour before bed to give your mind a chance to unwind.
- Develop a pre-sleep routine. Spend the last hour before bed doing something calming, like reading or meditating.
- If you can’t sleep, go to another room and do something relaxing until you feel tired.

If you’re still having trouble sleeping, talk to your health care provider, who can help identify the cause and recommend effective treatment so you can achieve sleep that refreshes and renews you.

Get more tips from the National Sleep Foundation:  
[www.SleepFoundation.org](http://www.SleepFoundation.org)

**Psycho-Oncology**  
Journal of the Psychological,  
Social and Behavioral Dimensions of Cancer

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