

# LTFU NEWSLETTER

## 2018: ISSUE 1

### RESEARCH UPDATES

## Cognition Module

Starting Summer 2018, we will have a new supplemental questionnaire that pertains to cognitive function (one's ability to think), which will run until the end of Summer 2019. While recent surveys have dealt with post-traumatic stress disorder (PTSD), bone health, and fatigue, we have not yet focused on the cognitive decline that can happen after transplant. It is common to experience what you may have heard called "chemo-brain", which more generally refers to "brain fog" or trouble thinking. Some of what we will be asking you about is your recent mood, memory, quality of sleep, and concentration.

We know these extra questions in addition to the core questionnaire can be time-consuming; however this information is valuable in helping us understand people's functioning across the spectrum after transplant, whether you are 6 months out or 40 years out. As always, we appreciate your continued involvement in our studies, and the time you take out of your day to help us in our research. Whether or not you feel you are doing well, your information is equally valuable.

"Our patients have been asking us to look at cognitive problems after transplantation, so this year's module is devoted to this topic," said Dr. Stephanie Lee, research director of the LTFU program. "There are so many questions we could ask our patients, but to try to keep the survey to a manageable length, we limited ourselves to questions that have been used before to investigate "chemo-brain" in other cancer survivor populations." Dr. Eric Chow from Fred Hutchinson assembled a group of experts from around the country to choose the questions. "I hope that many people participate, whether or not they are bothered by these difficulties, because that's how we'll figure out how the entire population is doing."

At the end of the module you will be given an opportunity to tell us if you are interested in potential future studies that will be designed to help transplant survivors. These potential studies are still in development but by letting us know of your interest, you will be placed on the list to receive information about any future studies and on how to participate.

## PTSD Study

Between the period of July and December 2016, LTFU sent out surveys to over 2,000 patients and caregivers regarding post-traumatic stress disorder (PTSD), which is characterized (in the context of our study) by suffering from recurrent negative thoughts, avoiding thinking about and remembering transplantation, and experiencing increased irritability for at least a month. The study required participants to be adults, as well as being at least six months post-transplant.

By the end of 2016, we were able to use just over 1,000 completed responses in our study. While this is quite a large number of surveys to work with, it highlights why we need as many responses from survivors as possible. The higher the response rate, the more accurate an image we are able to paint of the survivor experience. The returned surveys were completed by mostly patients, with roughly a third of total responses coming from caregivers.

We found that the vast majority of our respondents do not suffer from PTSD, although there were many that had symptoms of PTSD, but not enough to qualify for a diagnosis. Perhaps somewhat surprisingly, results showed that caregivers (7%) were more likely to meet the criteria for PTSD than patients (3%). Spouses providing care to their significant others have reported things such as more loneliness, less spiritual well-being and lack of social support.

These findings are consistent with other research according to Dr. Heather Jim, PhD, Associate Professor at the Moffitt Cancer Center and a collaborator on the study. "Other studies of cancer patients not treated with BMT (Bone Marrow Transplantation) and their caregivers have also found that caregivers are often more distressed than patients. For caregivers who are distressed, this means you are not alone – other caregivers feel the same way. It's important for both patients and caregivers to take care of themselves and talk to their doctor or mental health professional if they feel distress that interferes with their ability to get through the day." In addition to our nursing line we also offer a support group for patients and caregivers to share and listen to other survivors on the first Thursday of every month. If interested, simply contact us via phone or e-mail.

# LONG-TERM FOLLOW-UP NEWS

## Chronic GVHD & QOL

In 2015-2016 we asked patients about chronic GVHD and their Quality of Life. Of the nearly 3,000 surveys mailed out, approximately 45% were returned. Among those who responded, about 19% reported their chronic GVHD was mild, 8% reported their chronic GVHD was moderate and nearly 2% of participants reported severe chronic GVHD. About 27% reported never having chronic GVHD and about 20% had chronic GVHD that later resolved. 24% skipped the chronic GVHD question. People who reported moderate or severe chronic GVHD reported worse quality of life, worse functioning, and were more likely to be taking prescription medications for pain, anxiety and depression compared to those with resolved chronic GVHD.

Quality of life was similar between people with resolved chronic GVHD and those who never had it. Between 27-39% of people with active chronic GVHD were unable to work due to health reasons, compared with 12% whose chronic GVHD had resolved and 15% who never had chronic GVHD. Mouth, eye and nutrition symptoms persisted after resolution of chronic GVHD.

We have an active clinical research program with trials available to people who are newly diagnosed with chronic GVHD and those who have had it for a while. Please call or email us at the contact info below if you are interested in finding out if you are eligible for a clinical trial.

## Personalized Data

As mentioned in the previous newsletter, we are trying to find more ways to share information with you. This year is our first attempt to give back to you individual information from your surveys. If you completed the fatigue module last year, a separate letter will be included with your annual questionnaire packet that gives you your personal results. Information on how to interpret your score is included, as well as a list of helpful resources. If you would like to talk to someone in LTFU about your results, you suffer from severe fatigue, or you would like the list of resources, please contact LTFU at 206-667-4415 or by email at [replylftfu@fredhutch.org](mailto:replylftfu@fredhutch.org).

## Online Questionnaire

We have observed an increase in the number of responses coming from our online questionnaire option; however we wanted to make sure all patients are aware of this alternative way to sending us back your questionnaire and helping us with

our research. The online questionnaire asks the same questions as the paper version we mail out every year. Some of you may find this method more convenient as the questionnaire can be completed on both your personal computer as well as through your mobile device. Instructions on how to complete it online are provided with each questionnaire packet.

For those of you who prefer to complete the questionnaire online, you may choose the option of being sent an email each year notifying you that your online survey is ready to complete, instead of receiving a paper version in the mail. To opt-in, select the "online only" option at the end of the online questionnaire or just contact us with your personal e-mail address to let us know you prefer to complete the questionnaire online. The e-mails will include links to resources that we generally include with the usual physical packet so you are not missing out on any important information.

We hope completing the online PRQ is a more convenient way for some of you to participate in our research. Completing the questionnaire online ensures that we receive your answers instantaneously, while also helping us save on printing and postage costs. It also saves us time because you are entering data that will go directly into our database as soon as you hit "submit." The online PRQ also offers participants a way to conveniently upload documents (such as medication lists) that you think might be relevant to us. It is completely acceptable if you prefer the paper copy. Your data is equally valuable and will be treated as such.

## Newsletter Feedback

It is our hope that our newsletters are a valuable and interesting addition to your annual patient recovery questionnaire packet. The Newsletter is intended to keep you informed about research topics both past and present. However, we want to make sure the topics we cover and the data we relay back to patients and caregivers is useful. This is why we are encouraging patients who are readers of our newsletters to offer suggestions on topics that might be of interest to you, other patients, and caregivers. Feedback is not limited to the Newsletter or Questionnaire; we welcome and look forward to any and all suggestions about the various aspects of the LTFU research program.

### CONTACT

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### Feedback/Questions

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