

LTFU NEWSLETTER

RESEARCH UPDATES

COVID-19

Who would have anticipated at the end of 2019 that 2020 would be dominated by COVID-19? In March 2020, the Transplant Program at Fred Hutchinson, the Seattle Cancer Care Alliance, and University of Washington took immediate steps to ensure the health and safety of our patients and staff. This included vigorous screening, delaying non-urgent transplants, closing clinical trials to enrollment, cancelling long-term follow up (LTFU) visits, and careful isolation of anyone with concerning symptoms. [As of this writing, June 2020, no transplant patients or staff have been infected.](#) However, we remain vigilant as the transplant program returns to normal activity, clinical trials reopen and LTFU visits resume. It has been difficult balancing the risks of COVID-19 with the risks of delaying transplants and evaluations, since our overall goal is to treat and cure as many people as possible while managing treatment complications.

For those of you who would like more cancer-specific information about COVID-19, please see the FAQs on our website at <https://cutt.ly/Wi4vLGD>. The LTFU also is available to answer your questions that are not answered by that document.

Many of you have had your LTFU appointments converted to telehealth visits. We are pleased to be able to offer these visits but remember that a comprehensive evaluation requires an in-person visit. If we need to do a physical exam to evaluate you for potential complications or to see if a treatment is working, please schedule an in-person visit.

For general information on COVID-19, <https://cutt.ly/Hi4QvHY> provides information on how vaccines are developed, how the pandemic was tracked, and other information about research into COVID-19.

Stay safe and be well.

Late Infections for Transplant Patients

Many people have contacted LTFU to inquire about their risks during the pandemic. Some people have even mentioned on their Patient Recovery Questionnaires that their answers are more reflective of the COVID-19 restrictions than their usual health. We know that many of you are feeling vulnerable and isolated. We understand your concerns.

The risks of COVID-19 to you, now that your transplant is possibly years behind you, are not yet known. Some studies show higher rates of severe disease and death with COVID-19 infections but most of these reports are about people undergoing transplant or who are early post-transplant. However, we know that anyone who has had a transplant is at a higher risk for getting infections. A study conducted by Fred Hutch before COVID-19 found that HCT (hematopoietic cell transplantation) survivors who were two or more years post-transplant had a significantly increased risk of infection when compared to the general population and other cancer survivors. The most dramatic increase in infection type was respiratory infections. The study was based on over 1,700 WA state HCT survivors treated from 1992-2009, compared to 5,455 non-HCT cancer survivors and over 16,000 non-cancer residents.

This study highlights the need to be vigilant about infection risks and to keep current on your vaccinations. You can take steps to stay safe. Keep at least 6 feet from people who do not live with you, wear a mask in public and make sure others around you wear one too, avoid sick people, and wash your hands often.

Online PRQ

Ever since the pandemic started we have seen a higher than usual return rate of our questionnaires, both in our paper format but also through our online option. The LTFU team greatly appreciates your much-needed responses in either format. The information you provide on your questionnaires is incredibly valuable to our ongoing research at Fred Hutch. With the pandemic, more people are using online resources and seem to feel comfortable with computers so we would like to remind you that you can complete your surveys on your personal computer or mobile device. The code to access your survey is included in your Patient Recovery Questionnaire Packet. If you have lost your code or need help completing the online questionnaire, you may give us a call (206-667-4415) or email us (replylifu@fredhutch.org) and we will be happy to help you. Additionally, you may also contact us to request another paper copy of the questionnaire.

New Module

This year's supplemental research module is about muscle cramps and neuropathy. We know that many of you have these symptoms and that they started after your transplant. Yet, there is very little information in the literature to know how frequently they occur, how severe they are, which treatments have been tried and how much they interfere with quality of life. Whether you have experienced significant, mild, or no symptoms of neuropathy and/or muscle cramps, please complete this survey and let us know. It is important that we hear from both people who have these symptoms and those who do not, so that we can analyze the risk factors and try to develop better treatments.

Sexual function

Several years ago, the research module was about sexual functioning. We asked adults about their sexual activity and sexual well-being. We found that after a transplant, both men and women were less likely to be sexually active and if active, were less likely to have high sexual well-being compared to people of similar age who did not have a transplant. While we know that some people prefer to be abstinent, overall we found that those who said they were sexually inactive or had low sexual well-being also reported more distress, depression and not feeling strong and healthy or recovered from transplant. Both men and women reported lower sexual interest or desire than adults who had not had transplants. Men reported issues with erectile function and women reported vaginal dryness and pain. If these issues are bothering you, please bring them up with your doctor to find out what can be done. There are some medical reasons that you could be experiencing these symptoms, and there are treatments that can help. Sometimes relationship counseling is also helpful.

Additional resources are available at:

A study to improve sexual functioning after HCT
<https://cutt.ly/YiBEMXF>

American Cancer Society answers for men
<https://cutt.ly/PiBPRrw>

American Cancer Society answers for women
<https://cutt.ly/RiVnmcs>

National Institutes of Health guidance for cancer survivors
<https://cutt.ly/miVn2PY>

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Feedback/Questions

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