

LTFU NEWSLETTER

LTFU Clinical Leadership

Starting in January 2021, Dr. Paul Carpenter will become Clinical Director of the Long-Term Follow-Up Unit (LTFU), taking over a position Dr. Mary Flowers has held since the formation of the Seattle Cancer Care Alliance (SCCA) in 2000. Dr. Flowers will continue to be involved as an attending in LTFU and as the Principal Investigator of clinical trials. Under Dr. Flowers leadership, LTFU has trained physicians from across the globe who are interested in late complications and chronic graft-versus-host disease. The LTFU program currently supports more than 6,500 transplant survivors.

Dr. Paul Carpenter has been at Fred Hutch since 1995. He has been serving as the Clinical Director of the Pediatric Blood and Marrow Transplant Program since 2014 but will be stepping down from that role to assume the Medical Directorship of the adult LTFU program. We welcome Dr. Carpenter to his new role!

COVID-19

Since the beginning of the pandemic, the safety of our patients and staff has been the number one priority of Fred Hutch and the SCCA. The protections put in place have included additional screenings, COVID-19 testing, as well as adapting to patients' needs and doing whatever is necessary to ensure the safety of patients who make any in-person visits. By the time you read this newsletter, it is possible that a SARS-CoV-2 vaccine may be available to you. Many BMT survivors may be understandably hesitant about in-person visits but can be assured that once on campus, strict infection control procedures are being followed. If you have any questions about any of your upcoming visits, please feel to contact the LTFU Department (206) 667-4415.

If you are interested in learning more about cancer-specific COVID-19 information, please refer to <https://seattlecca.org/COVID19>.

Peer-to-Peer Connection Program

The Blood and Marrow Transplantation service has launched a Peer-to-Peer Connection Program and is looking for mentors like you! This program provides a unique opportunity for individuals who have experienced a transplant to use their personal experience to help other SCCA patients beginning their care journey. If you choose to become a Peer-to-Peer Connection mentor, you will be asked to complete a short application, a two-hour online training, and a phone interview. Following this process, you will be matched with a patient for a one-time phone conversation. If interested, please contact any member of your SCCA care team or email Volunteer Services at volunteer@seattlecca.org. We look forward to hearing from you!

Return-to-work Survey

One of the challenges that many survivors see after transplantation is the path of returning to the workplace. Employment has many benefits to survivors outside of providing a steady income and maintaining health insurance. Work provides an environment where one can stay socially engaged with others throughout the day and can be a primary source of purpose and self-esteem. This is one of the reasons why it is so important to look at the type of support that survivors receive when returning to work.

LONG-TERM FOLLOW-UP NEWS

Last year, we may have asked you to complete a supplemental survey in addition to the annual patient recovery questionnaire. This optional survey was distributed to people who were between 1-5 years post-HCT at the time of the survey. The goal of the survey was to examine if survivors were receiving RTW (Return to Work) support, and if they were, what type of support they received and whether it was helpful in their transition back into the workplace.

The results showed that there was a lack in support across multiple areas in the approach to RTW. Although approximately half of survivors who responded to the survey stated they had discussed returning to work with a healthcare provider, the majority (about 9 out of 10) told us they did not receive any resources or assistance in the RTW process. According to a survey of transplant center directors in and outside the United States conducted by doctors at our center in 2017, 87% of the 45 transplant centers that responded reported that returning to work is a problem for their patients, but only 36% of these centers have a RTW program in place (counseling, videos, or reading materials). Returning to work can be a complicated process after recovery. The participants who completed the transplant director survey, as well as survivors who responded to the survey distributed by LTFU, have told us what they would like to see in a RTW program, such as counseling (including advice on disability benefits), support from a physical therapist, as well as advice on common issues with RTW and creating a plan on the RTW process. Half of people thought that RTW support should begin before transplant (40%) and half wanted this information when they were ready to return to work (43%). The next step will be to interview

some of the participants of the LTFU study to help us to develop an RTW support plan for present and future transplant survivors at our center.

As transplant centers work to improve on this area and potentially develop RTW support plans in the future, people can reach out to their care team to be provided with helpful resources including advice on how best to approach RTW as well as benefits information. Online resources on BeTheMatch.org, BMTinfo.net, as well as CancerandCareers.org also have information relevant to the RTW process.

Online PRQs

The information you provide on your questionnaires is incredibly valuable to our ongoing research at Fred Hutch. Filling out your survey online also helps us by decreasing the resources needed to enter the data from paper forms. 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 (replyltfu@fredhutch.org) and we will be happy to help you. Additionally, you may also contact us to request another paper copy of the questionnaire. Thank you for your partnership in improving survivorship care!

CONTACT

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Feedback/Questions

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Read past, present and future newsletters online:
https://cutt.ly/info_for_patients