LTFU Newsletter

Fred Hutch
Cancer Center

New Survey Module

The July 2025-June 2026 module will ask you about your health, diet and exercise habits to better understand our patients' engagement and interest in "lifestyle" medicine. Lifestyle medicine is having healthy habits in order to minimize the risk of medical conditions and to live as long and well as possible. You may have heard about this movement because it is not just for transplant and immunotherapy survivors – the general population is engaging in these behaviors too. Some of the questions ask whether you are interested in providing additional feedback about these topics. We may reach out to some of you who express interest. Thank you as always for helping us to understand your experiences after your treatment and to partner with you to protect and maintain your health.

Study Results/ Sclerosis

Dr. Stephanie Lee is working on a new patient-reported outcome survey for people who have sclerotic chronic GVHD. Sclerotic cGVHD occurs when the skin and underlying tissue hardens and thickens. This can cause difficulty moving joints, firm tissue under the skin that looks like "cellulite", or even arms and legs feeling like "sticks" and not healing well if the skin is injured. About 10-20% of people with chronic GVHD have sclerosis. LTFU has been working to improve detection and treatment of this type of chronic GVHD. Working with 36 Fred Hutch patients, Dr. Lee and her colleagues developed a 55-question survey based on what you told her team about how sclerosis was affecting your life. This article has been published in a medical journal (*Blood* 2025), and additional work is ongoing to "validate" it and make sure it is ready for researchers to use. Keeping with the theme of sclerosis, we will be starting a new study of axatilimab for treatment of sclerosis that has been present for less than 6 months. Axatilimab is an i.v. drug given every 2 weeks that was approved by the FDA in 2024 for treatment of chronic GVHD. 50 people will be studied, and the study will also be opened at two other transplant centers (Dana-Farber Cancer Institute in Boston and Moffitt Cancer Center in Tampa). For this study, we want to focus on people who have had sclerosis for a short period of time because we think they are more likely to respond to the drug.

Faculty Spotlight

Rachel Salit, MD

Dr. Rachel Salit is a hematologist and oncologist and member of the stem cell transparent faculty who joined the Fred Hutch Cancer Center in 2012. Long before she even began her research here, Dr. Salit was well aware of the reputation that FHCC held, "Fred Hutch has been well known as the Mecca of stem cell transplantation for as long as I can remember and from the time I started my fellowship at the National Institutes of Health (NIH), I knew I wanted to work here someday."

When asked about what sparked her interest in her areas of expertise and more specifically in Survivorship she stated that following patients over time has always been very rewarding for her. "At the point we see patients in the LTFU, we are less focused on curing their disease and more focused on helping them achieve their future life goals. Many patients change their views on what this means once they have survived cancer."

Looking towards the future of research in Survivorship, Dr. Salit is leading a study, in which many of our current Patient Recovery Questionnaire recipients participated in and contributed to her research.

"One of my current research studies is a pilot program to support patients in meeting their return-to-work goals following stem cell transplant. The study enrolls patients even before they have their transplant and provides them with early access to rehabilitation counseling and rehabilitation medicine experts. We are aiming to help patients maintain their strength, cognition, and mental health during the transplant period as well as provide patients with tools to communicate better with their employers and ask for needed accommodations. We enrolled our first patient in March 2025 and I'm very excited to see the impact we can make in this area."

Reflecting on the time since she first joined the Fred Hutch she noted “our ability to achieve long term cures for patients has increased greatly and quality of life due to decreased chronic graft versus host disease has improved so much too. While we are not successful at curing everyone, the fact that survivorship has become central to clinical and research goals, speaks volumes in terms of how far we’ve come.”

Lastly Dr. Salit wanted to extend a message to all those who completed the survey. “I would like to say thank you to all the LTFU survivors who completed the return-to-work survey included as a supplement in the LTFU annual survey between 2019-2020. With your support and suggestions, we were able to create a return-to-work support intervention which is hopefully useful to future patients. “

Kate Sortun, ARNP

Kate Sortun has had a long 13 years of experience in the Fred Hutch transplant clinic. For her, the motivating factor to pursue a career in oncology was a personal one. “I had always wanted to work in oncology since the 4th grade, when my dad was diagnosed with CLL...although at that time I thought I was going to be in the lab at Fred Hutch curing cancer. He went on to have a transplant when I was in the 6th grade, so I guess I felt naturally called to work in transplant. But it wasn't until high school or maybe even college where I realized I wanted to be involved directly in patient care.”

When asked about some of her rewarding experiences working in the Fred Hutch transplant clinic, she mentions the opportunity to learn from some of the most respected leaders regarding the advancement of transplantation and chronic GVHD. However, the highlight of her time at the Hutch has been the personal connections she has made. “What has been most rewarding about working directly in patient care has been working as part of the team with individuals, and their families, as they navigate through transplant and the late effects. I love getting to hear little bits about my patients' families, milestone events such as the birth of a grandchild or a child graduating from high school, local and international travels, etc. What a rewarding feeling to know I was a small part in helping them be able to get to and enjoy those moments. I look forward to many more years at the Hutch and seeing what new advancements are made in transplantation and GVHD management as a result of the hard work put in by the study teams and the patients”.

Patient Resources

Patient Experience Helps Others

Now matching mentors with new patients!

Do you know a patient or caregiver interested in providing peer to peer support by talking with a newly diagnosed patient or a caregiver, or a patient/caregiver dealing with a recurrence?

In the Peer-to-Peer connection program, patients and caregivers at Fred Hutchinson Cancer Center (Fred Hutch) are offered the opportunity to talk with someone who has received treatment (or cared for someone who has received treatment) at Fred Hutch. All volunteer mentors must be willing to complete an online application, background check, orientation, and training modules. For more information you can reach out to Volunteer Services at volunteer@fredhutch.org Or call (206) 606-1935.

Use MyChart to link and share your medical records

If your doctor’s office uses EPIC as its medical record system you can use MyChart to link your account to the FHCC/University of Washington so that your health information is available to all people taking care of you. You can also use this link, or scan the QR code to check if your doctor’s office or medical facility uses MyChart.
https://www.mychart.com/LoginSignup

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Feedback/Questions

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