LTFU Newsletter

Fred Hutch
Cancer Center

Next 5-Year Reunion

A date has been set for the next Fred Hutch Transplant Program reunion! Please mark your calendars for Saturday, July 17, 2027. More information to come.

Upcoming Survey Module

Our next module focuses on recovery and return to social roles. Many people find it challenging to resume their roles as workers, parents/children, friends and community members after the arduous experience of transplantation or immunotherapy. Reintegration and thriving in a “new normal” can be challenging. The module questions are designed to understand satisfaction with your current roles. Please consider filling it out, whether you were treated last year or decades ago.

Study Results

Dr. Emily Liang analyzed the fear of cancer recurrence (FCR) module that was sent out from July 2023-June 2024. About 1,500 of you completed the module and about 1/3 had clinically significant levels of FCR. Not surprisingly, FCR was particularly high in those <5 years after treatment, those treated for myeloma, or who were on maintenance therapy to try to prevent disease relapse. FCR was associated with decreased well-being, worse quality of life, and higher anxiety with clinic appointments. In the comments section, several of you shared that seeing a physician and having tests is very anxiety-provoking and feels like PTSD. Treatment for FCR is psychological support which focuses on adaptive coping, i.e., not trying to convince you to stop worrying but helping you cope and feel better in the face of worry. Please let your care team know if you are suffering from FCR. https://www.fredhutch.org/en/news/spotlight/2026/05/crd-liang-trans-cell-ther.html

Dr. Masumi Ueda Oshima has been analyzing blood samples from people and their donors decades after transplantation to see how similar or different bone marrow cells are after they have spent many years separated in different people. Her results are overall reassuring that the donor’s stem cells are stable and functioning normally. Analyses are ongoing and she is planning to expand her study to include more people, so you may be invited to participate in the future.

Upcoming Studies

Dr. Catherine Lee’s study “PREZERVE” is actively enrolling patients soon after transplant who are interested in using an app to track posttransplant symptoms, including early signs and symptoms of chronic GVHD. She hopes that this symptom app will facilitate early communication of patients’ posttransplant concerns to healthcare providers and allow early intervention. Study staff review information provided through the app and work with LTFU to provide appropriate follow-up.

Dr. Stephanie Lee is collaborating with colleagues in Boston to study how peer support can help people going through transplantation. A pilot study showed that training former patients to be peer mentors and matching them up with current patients can benefit both. While Fred Hutch has a patient/caregiver peer mentoring program, few transplant patients participate in it. If NIH funding is granted as expected, we will be opening a study here in the next year. By formally studying how best to train and support peer mentors, and how exactly their involvement is helping patients and caregivers, we hope to expand the types of supportive care that we provide to our patients to help them get through transplant and speed recovery.

Patient/Staff Spotlight

From Patient to Philanthropy

Michael Rubin was a patient at the Fred Hutch Cancer Center nearly four decades ago. After his transplant, he would return to the organization to help it achieve its mission. Rubin reconnected with Fred Hutch through volunteer work in the early 1990's which helped reshape his career path and eventually led to his current role as Senior Director of Philanthropic Gifts at Fred Hutch.

"I wanted to give back to the place that saved my life" Rubin said on what led him into the field of Philanthropy at the Fred Hutch. "While raising money for research is rewarding, the most rewarding things about my job are my interactions with prospective, current and former patients. I like to show them that good outcomes are possible."

Michael recently found himself affected by the Long-Term Follow-Up (LTFU) program. After a recent and profound visit to LTFU, he had a chance encounter with Dr. Kathleen Shannon-Dorcy who suggested he write about his experience.

A Story from a Patient's Perspective

"The Lightness"

At twenty-four, I came to Fred Hutchinson Cancer Research Center in Seattle from New York for a bone marrow transplant. My younger sister was my donor; my mother became my care partner; my father and older sister visited frequently. I endured chemotherapy, total-body radiation, mucositis, and morphine dreams before my counts slowly recovered. I powered through, blinders on, telling myself "Be stoic, be strong – you have to summon an inner strength you never knew you had because ultimately, you are alone."

After discharge, I walked to the outpatient clinic three times a week, savoring the feeling of simply being outside. A friend's visit, a Mariners game, and my first cheeseburger marked steps back toward living. I pushed for normalcy fast — working in film production, attending nursing school, and working as a baker — searching for grounding, identity, and a future that made sense. But still, I carried decades of quiet vigilance and unprocessed fear. Until recently.

Thirty-eight years after transplant, a visit to the LTFU Department triggered an unexpected, overwhelming catharsis, a mournful sobbing that came from deep within. It turns out my mother was right – you can't go around your emotions; you have to go through them. She was also right in saying, "We're all part of a constellation." That day, my constellation expanded. Guided by a compassionate nurse, who caringly laid her hand on mine, she said, "You are not alone", and the weight finally lifted. My stoicism had buried the terror of facing my mortality deep inside me all those years ago. Being a Hutch patient again allowed me to go back in time and process that terror.

For the first time in decades, I felt whole — a lightness I hadn't known was possible.

Healing, I learned, can take a lifetime.

- Michael Rubin – Allogeneic transplant, 4/1/87

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Feedback/Questions

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