# LTFU Newsletter

Fred Hutch Cancer Center

## *Survey Module Results*

Last year we sent different supplemental surveys to different groups of people. Dr. Rahul Banerjee asked people who had been transplanted for myeloma about their experiences with "time toxicity" and financial toxicity. Dr. Mihkai Wickline asked people who were 1-8 years after transplant their opinions about vaccinations. Everyone else received a survey about whether they experienced positive feelings having gone through transplant.

## *Financial/Time Toxicity*

"Financial toxicity" is distress caused by having to pay for medical care such as copayments, deductibles, and coinsurance. High out-of-pocket costs can lead to significant financial stress, impacting a person's ability to afford necessary medical care and threatening their long-term financial security.

"Time toxicity" refers to time spent away from home due to cancer care and the burdensome impact that the duration and scheduling of cancer treatments can have on people's lives. It includes the time spent undergoing the treatment itself, and also the time spent managing appointments which can cause disruptions to usual daily activities. Ongoing treatment and everything associated with it can lead to both physical and mental stress.

Patients often have worsened side effects and decreased quality of life while on active treatment. For people in remission after stem cell transplantation for multiple myeloma, these toxicities may be unnecessary or truly toxic in terms of quality of life. The goal of the study was to ask whether people were experiencing time toxicity and financial toxicity, and to better understand the risk factors and effects on transplant survivors.

## *Key Findings*

Dr. Rahul Banerjee summarized his findings as follows: Financial toxicity rates were roughly the same regardless of disease status, with people in remission as likely to report financial toxicity as those on active treatment for relapsed multiple myeloma. While time toxicity was higher for people on active treatment as expected, 37% of patients in remission on maintenance also reported time toxicity. Time toxicity was defined as cancer-related visits, or phone calls at least once per week or in-person visits at least once per month among people living far from their treatment center.

For financial toxicity, there are several potential solutions. If we can identify people at risk of financial toxicity early in their cancer treatment, we can try to match them with resources that can help, for example better insurance or financial assistance programs. For time toxicity, we are focusing on patients on maintenance therapy - perhaps some patients do not need phone calls or in-person visits as often as we currently require them.

To read the published abstract, you may visit: *pubmed.ncbi.nlm.nih.gov/38521640/* You will be able to access the whole paper in a few months using this link.

## *Revaccination after Transplant*

Getting revaccinated after a hematopoietic stem cell transplant is necessary because transplant survivors are more likely to get a vaccine preventable disease (VPD) and are more likely to develop problems from a VPD than people who have not had a transplant. Survivors usually lose protective immunity from all pre-transplant vaccines within a couple of years after transplant, so we recommend that all survivors (allogeneic and autologous) get the entire childhood vaccine series after transplant. The revaccination process usually starts 12 months after transplant, and getting all the vaccines can take a year or more. We know from four previous studies from the US and Australia that not enough survivors are getting completely revaccinated, so we wanted to learn more about revaccination from Fred Hutch survivors.

## *Key Findings*

Dr. Mihkai Wickline summarized her findings as follows: First, we learned that 62% of people who answered the survey are completely revaccinated, 33% partially revaccinated, and 4% have received no vaccines. The

good news is that 77% of survivors not yet completely revaccinated plan to get completely revaccinated. Survivors who were further out from transplant were much more likely to be completely revaccinated than those closer to transplant. Survivors who did not receive their childhood vaccines as children or who reported slow immune recovery were less likely to be completely revaccinated.

Next, we learned that 69% reported high, 20% medium, and 11% low vaccine confidence. Those who reported low confidence expressed a distrust in vaccination, worry about harm from vaccines, and little benefit from vaccination. People who reported medium confidence expressed trust in vaccination and equal focus on potential harms and benefits from vaccines. People who reported high confidence expressed a significant belief in benefits, strong trust in vaccines, and minimal discussion about possible harms.

Finally, we learned that the odds of being completely revaccinated were about 30% higher with each reported facilitator and about 40% lower with each reported barrier. The most frequent barriers were the inability to receive live vaccines because of continued immunosuppression, finding a place in the community that will give childhood vaccines to adults, and delayed immune system recovery. The most frequent facilitators were having healthcare insurance covering vaccines and having a clear calendar of what vaccines to receive and when. From your responses, we learned that getting vaccines at Fred Hutch would be desirable.

You can ask your LTFU providers and nurses for assistance with revaccination either at an LTFU clinic appointment or by calling the LTFU Telemedicine line (206-667-4415). Your LTFU team can review your vaccine record and make recommendations, make sure you have the most up-to-date vaccine guidelines, communicate with your home providers if there is confusion, help you appeal your insurance if they are denying coverage for vaccines, and help you find places in your community that will give you vaccines. If you are not yet completely revaccinated due to immunosuppressive therapies for GVHD maintenance or chemotherapy, it will be important to think about getting your final vaccines once you are off these medications. That may be hard to remember since you may be on these medications for many years, so enlist the help of your caregiver and your local provider so that you do not forget. If you have any concerns about vaccination, please consider talking with your LTFU providers or nurses about your questions and to learn more about the benefits of revaccination. Due to VPD outbreaks with the under-vaccinated general population it is more important than ever that survivors are revaccinated to protect themselves.

## *Positive Psychology*

For those who completed the positive psychology survey module, thank you. We are still in the process of analyzing the results. We will share our findings in future newsletters.

## 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. 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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