

LTFU NEWSLETTER

UPDATES & ANNOUNCEMENTS

Clinical LTFU Announcements

We are pleased to inform you that SCCA transplant patients are now able to view and manage their care through the Caresi app. Caresi allows you to view your schedule and lab results, as well as care team contact information and educational materials. You can register and create an account by simply going to caresi.com. In addition to the webpage you can download the free Caresi app to your iOS device through the iTunes app store. If you have questions regarding Caresi, you can contact the support team via e-mail at caresi@seattlecca.org, or by phone (206) 606-6865. We encourage patients to try out Caresi and utilize its many helpful tools.

The LTFU telemedicine nurses continue their efforts to share their knowledge with nurses in the community who care for transplant patients. They hosted the second LTFU Nursing Summit in May 2019 where nurses came to the Hutch to observe telemedicine rounds, hear lectures about caring for BMT survivors and participate in Q&A sessions. This summit is a way to share knowledge with nurses in the community who care for LTFU patients and for the LTFU nursing staff to learn better ways to support the local teams. Between the two summits, 40 RNs attended representing oncology practices in Alaska, Hawaii, Washington, Montana, Idaho, Oregon.

Clinical LTFU also welcomes new staff to clinic and the telemedicine lines! Gemma Tamayo BSN, RN, BMTCN is new to LTFU clinic and brings a wealth of SCCA BMT nursing experience to her role. Laura McBride BSN, RN, OCN is new to LTFU Telemedicine and has a rich background of caring for BMT and oncology patients in Texas and Hawaii.

Research LTFU Announcements

In 2019 we were awarded a grant from the National Institutes of Health (NIH) to continue our studies on chronic graft-versus-host disease (GVHD). Many of you have participated in our chronic GVHD studies, either in clinical trials or through completion of surveys, and by donating your blood for research, and we thank you. The new study will be trying to “watch” chronic GVHD as it develops shortly after transplant to test early detection strategies. About 100 people from our center as well as NIH will be enrolled and evaluated every 2 months for the first year after transplant. This study will take several years to complete.

In other research news, we have analyzed information from the 2015-2017 survey and submitted a paper comparing people who had autologous transplants for lymphoma (non-Hodgkin’s lymphoma and Hodgkin

lymphoma) with those who had a transplant for multiple myeloma more than 5 years before the survey. We found that both groups still reported many medical and psychological issues even though their transplants happened more than 5 years before. In particular, there were high rates of shingles, cataracts, skin cancer, sexual issues as well as bone complications. People transplanted for myeloma were more likely to be taking medications for infection prevention/treatment, hypertension, osteoporosis and pain.

Finally, we continue to have new trials of treatments for chronic GVHD, although most require at least monthly visits to Seattle Cancer Care Alliance. Please contact us by the means listed below for more information.

(Continued on back...)

Upcoming Modules

Spirituality and Return to Work

The LTFU questionnaire is sent to each patient who consents to receive an annual survey, and about half of you fill it out each year. Thank you for helping us to better understand the patient experience. From July – December 2019, we will include questions about spirituality, for a study spearheaded by Stephen King, Chaplain at Seattle Cancer Care Alliance. We are interested in how the transplant experience may have affected you, positively and negatively, in this area.

We will also include a return to work survey for people who are 1-5 years after their transplant. The purpose of these questions is to understand barriers and motivations about returning to work, to identify things we can do to help. Dr. Rachel Salit is leading this study.

As always, your participation is voluntary, but we hope to hear from you so that our research results are representative of the entire patient community.

New PRQ Core Survey

Starting in January 2020, you will see a new CORE survey. Every 5 years we adjust the core survey to address new research questions. However, we don't change it every year because it is important to have several years of the same questions to see changes over time. The new 2020 core survey will be shorter and focus on questions that have been most useful to us over time. It will still include a section for your comments which we summarize in our "Thoughts and Comments" compendium. More of you are

completing the survey online. For those who prefer the paper version, you can still complete it that way. Please remember that if you have specific medical questions, you should contact the LTFU directly at 206-667-4415 or by email at LTFU@fredhutch.org.

Staff Profiles

Dr. Mary Flowers

Dr. Mary Flowers has been the director of the Adult Clinical Care Long-Term Follow-Up Program since 2000. Her beginning with the Fred Hutchinson Cancer Research Center started back to 1983, when she had a brief fellowship and worked alongside the Nobel Prize winning pioneer of bone-marrow transplantation, Dr. E. Donnall Thomas. She then returned to Fred Hutchinson in 1987, after developing a national bone-marrow transplant program in Rio de Janeiro in her home country of Brazil, which offered free access to such treatment to all eligible adult and pediatric patients. With well over three decades of working in the field of blood and marrow transplantation, Dr. Flowers has been at the forefront of both patient care and research for the thousands of patients that have been treated here.

"When I started the Clinical LTFU Service about 3 decades ago, who would have thought we would get so big? We are now following more than 6,200 people and the longest survivor is more than 47 years posttransplant." Such growth is a testimony of the advances in clinical research and collaboration that happens at the Fred Hutch.

CONTACT

Long-Term Follow-Up Program
Mail Stop LF-240
PO Box 19024
Seattle, WA 98109-1024
Tel: 206.667.4415

Feedback/Questions

replylifu@fredhutch.org

Missed an issue?

Read past, present and future newsletters online:
fredhutch.org/lifu/newsletters