

# LTFU NEWSLETTER

## Honoring Dr. Mary Flowers

After 30 years as the Clinical Director of the LTFU, Dr. Mary Flowers will retire in December 2022. It is hard to imagine the LTFU without Dr. Flowers since she built the program and has nurtured it all these years. She recognized long before the rest of the field that transplant survivors have unique physical and psychosocial needs. She has devoted her career to improving our understanding and treatment of these complications, which often occur long after people have had their transplants.

Dr Flowers has cared for many people reading this newsletter. She is an international expert in managing chronic GVHD and late complications. She will continue to work with her Brazilian colleagues, helping them to develop LTFU and clinical research in that country. We will miss Dr. Flowers' incredible clinical experience, her quick smile and her outstanding care of patients (and her motherly care of colleagues!) but we are happy she is going to be able to relax and enjoy her retirement. She plans to spend more time with her daughter's family in California including her young grandson.

## Fred Hutch – SCCA Merger

For two decades the Seattle Cancer Care Alliance (SCCA) has been delivering outstanding cancer care adjacent to the Fred Hutchinson Cancer Research Center on its South Lake Union campus. SCCA began as a partnership in 1998 between Fred Hutchinson, University of Washington Medicine, and Seattle Children's Hospital, bringing together the three institutions to deliver outstanding cancer care.

On April 1<sup>st</sup>, 2022, the Fred Hutchinson Cancer Research Center and Seattle Cancer Care Alliance officially merged to be unified as the organization now known as the "Fred Hutchinson Cancer Center." While

"Research" was removed from the organization's name it does not indicate a change in our commitment and dedication to research. From a patient's perspective, this merger should have minimal impact. The current doctors and care team that patients have seen or are seeing at the clinic will not change as a result of the transition to the Fred Hutch Cancer Center. The construction of the new wing of the clinic continues and will greatly expand the clinical space.

## COVID Update

Thank you to all who completed the COVID-19 survey module. We will be finishing data collection in June 2022, then will be analyzing results in collaboration with our infectious diseases colleagues. We are learning a lot about how the SARS-CoV-2 virus affects immune compromised people. For example, we studied 38 people with chronic graft-versus-host disease on immune suppressive medications who were vaccinated with one of the COVID vaccines. Although 75% had a good antibody response, 25% did not seem to develop a protective immune response. We also performed a special test to see if the cellular part of the immune response had been stimulated by the vaccine. We found evidence of a response in about half of people but the other half did not have a detectable cellular response. Now that we have monoclonal antibodies and better anti-viral medications, we have more ways to protect you but vaccinations still are an important part of our armamentarium. We recommend you stay up to date on your vaccinations (all of them, not just COVID) and continue to follow general guidelines for avoiding infection. If you are interested in cancer-specific COVID-19 information please refer to <https://www.seattlecca.org/covid19>

## New Study Results

In 2021, there were 2 new medications approved by the Food and Drug Administration for treatment of chronic graft-versus-host disease (ruxolitinib and belumosudil). This is an exciting development because it gives us more options to treat chronic GVHD. Both medications are pills and seem to be generally well tolerated without bothersome side effects or need for blood draws to monitor levels. We continue to study other treatments for chronic GVHD, as well as ways to prevent this complication from happening in the first place.

Last year's survey module asked about neuropathy and cramps. We have analyzed the data and the results were surprising (at least to us). A very high proportion of you reported recent bothersome neuropathy or cramps, and the rate is about equal in people after either autologous or allogeneic transplants and persists years after transplantation. These results have been submitted for publication and suggest that we are not paying enough attention to these symptoms. Please talk to your doctor if you have these symptoms.

Drs. Wu and Chow analyzed data from the "Thinking" module that was sent to you in 2018-2019. Overall, 1861 people returned the module and were included in the analysis. Quality of life related to cognitive functioning (thinking clearly) was similar to the general population, although people with hearing loss and poor sleep were more likely to report lower quality of life.

We continue to analyze data from past surveys. Drs. Syrjala and Langer completed two analyses based on the 2015 sexual functioning and relationships survey. Dr. Syrjala found that women were more likely than men to report being sexually inactive in the past year (39% vs.

27%) and, among those sexually active, to report low sexual function (64% vs. 32%). Male and female survivors reported lower rates of sexual activity and function than the normal population.

Dr. Langer analyzed self-reported data from 1047 married survivors. On average, survivors' ratings of the quality of their marriage were comparable to published community sample values and better than those in couples therapy, but 19% reported that their relationship was causing distress. "Relationship-distress" for men was associated with longer time since transplantation and greater distress related to their prior cancer and treatment. For women, "relationship-distress" was associated with depression. Please talk to your medical provider if you have questions about these issues.

## 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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