Finding Quality of Life and Support When Living with Chronic Graft Versus Host Disease (cGVHD)

November 9, 2022
12:00-1:30 pm EST

nbmtLink
National Bone Marrow Transplant Link
30 YEARS 1992-2022
Presentation Outline

Introduction to nbmtLINK

Dr. Stephanie Lee, Professor at the Fred Hutchinson Cancer Center and the University of Washington, Associate Director of the Clinical Research Division and the Research Director of the Transplant Long-Term Follow-Up Program
Issues related to quality of life while experiencing cGVHD

Taisel Losada, PsyD, LP of Henry Ford Cancer Institute
Psychological, behavioral, and social factors that impact the cancer population and ways to find emotional support, and coping mechanisms

Peter Gordon, a long-time survivor of AML who had a transplant in 2008. Peter wrote his memoir “Six Years and Counting: Love, Leukemia, and the Long Road Onward” and will share how he is living his best life as he deals with chronic related conditions.

Question and Answer Period
Our Mission

The National Bone Marrow Transplant Link (nbmtLINK) is dedicated to helping individuals and their families from diagnosis through survivorship. We work with hospitals, cancer centers, and other organizations to reinforce and complement medical care by providing resources, support and education.

We link you to experts across the country in all topics related to transplant and to others who have made it through the journey before you.

Please feel free to email us for more information, slides, or assistance

Peggy Burkhard, Executive Director, peggyburkhard@nbmtlink.org

Jennifer Gillette, LMSW, Staff Social Worker jennifergillette@nbmtlink.org
Resources to Help Families Navigate the Transplant Journey

- Lunch & Learn Programs, podcasts, multiple webinars, and blogs from those who have been through the transplant process on all things related to transplant including disease specific information, survivorship issues, coping, and symptom management.

- Peers Support Mentor Program for Patients and Caregivers

- Second Birthdays Recognition Program

- Resource books, materials, emotional support from a licensed social worker and referrals

- Resources and stories of support via our Facebook page
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Our esteemed Link Partners for their continued support in all we do
Today’s presentation is meant to inform and support, it is not intended to replace individualized medical advice.

nbmtLINK and the presenters do not recommend or endorse any specific products, therapies, websites or clinical trials. The treatments, therapies, products, trials and websites mentioned during the webinar are provided as a convenience to you and to promote dialogue between you and your health care team about supportive care approaches in chronic GVHD. Before adding any new approach or treatment to your regimen, you should discuss this with your health care provider to determine if that intervention is right for you.
Dr. Stephanie Lee is a Professor at the Fred Hutchinson Cancer Center and the University of Washington, Seattle, WA. She holds the David and Patricia Giuliani/Oliver Press Endowed Chair in Cancer Research. She is also Co-Scientific Director of the CIBMTR Immunobiology Working Committee. At Fred Hutchinson, she is the Associate Director of the Clinical Research Division and the Research Director of the Transplant Long-Term Follow-Up Program. She was the 2020 President of the American Society of Hematology. Her research focuses on outcomes after allogeneic hematopoietic cell transplantation, especially chronic graft-versus-host disease, and includes the patient experience as measured by patient reported outcomes (PROs).
Dr. Taisel Losada is a clinical psychologist specialized in the psychological, behavioral, and social factors that impact the cancer population. She received a master’s and doctoral degree in clinical psychology from Nova Southeastern University in Ft. Lauderdale, Florida. She then completed her internship at Henry Ford Hospital in Detroit, MI, and concluded her formal training with a fellowship at the University of Wisconsin, Madison, where she treated those with severe burns and cancer diagnoses. She was excited to return to Henry Ford in 2018 as a psycho-oncologist working within stem cell transplant and general oncology. She enjoys running the inpatient Psycho-Oncology consultation service, and working with stem cell transplant candidates and caregivers throughout their transplant journey. She hopes to continue improving access, quality of care, and support to staff as she continues on her journey as a proud member of the Henry Ford Cancer team.
Peter Gordon is a corporate education facilitator/coach, with a focus on business writing and managerial skills. He's also a writer and public speaker for the cancer and medical community. In 2008, Peter had a bone marrow transplant for AML. He chronicled his transplant and the challenging years afterward in his memoir “Six Years and Counting: Love, Leukemia, and the Long Road Onward.” He continues to grapple with chronic GVHD to this day, and is constantly striving to live the best life possible with his conditions. He’s also a passionate advocate for promoting bone marrow donor awareness and registration. Peter lives in Falmouth, Maine, where he enjoys hiking, skiing, and bicycling along the coast in search of the perfect lobster roll.