LRF Annual Forum Lymphoma Survivorship Session Presenter: Eden Bauer, PhD., RN, UCLA Health

71% of people with NHL’s are surviving at least 5 years, and there is a growing number of 15+ year survivors. The Survivorship definition used by the National Cancer Institute’s Office of Cancer Survivorship, established in 1996, states: 1. Survivorship starts at time of diagnosis, not at the end of treatment, through the balance of his/her life. 2. Includes family, friends, caregivers, and supporters, all of whom are impacted by the survivorship experience. 3. Encompasses the physical and psychosocial effects of cancer diagnosis and treatment of initial treatment. 4. Focuses on the health and life of a person with a history of cancer beyond the acute dx and treatment phase. 5. Aims to optimize a person’s health after cancer by preventing or mitigating adverse outcomes post dx and treatment and promotes a healthy lifestyle and habits. Therefore, Survivorship care should start during initial treatment planning and must start by the end of initial treatment.

While long term health issues (“Long term effects”) parallel overall aging issues, certain cognitive and physical effects from the treatment itself, ie., “chemo brain” or neuropathy, that can be permanent for some survivors. “Late effects” such as secondary cancers, lung, or cardiac issues are more related to the chemo type, age, general health and lifestyle, genetics/family history than the NHL subtype. Survivors need an individualized approach that includes:


Federal NCCN Standards require oncology practices to help patients develop a Survivorship Care Plan, a multifaceted document outlining patient’s history, current treatment, post treatment care needs, and delineates roles for care team members. The standard to develop Survivorship Care plans is more prevalent in large academic practices, less so in community settings and small practices. Since most session participants have not been offered the opportunity to develop a plan and Coordinated survivorship care requires COMMUNICATION, session participants were advised to visit LRF’s website: lymphoma.org/publications to download a blank Lymphoma Care form, and canceradvocacy.org, the website for the National Coalition for Cancer Survivorship for more information about Survivorship care.