Li-Fraumeni syndrome (LFS) is a hereditary cancer syndrome that leads to an increased risk of multiple cancers. In the past five years new screening protocols have been developed that provide improved screening options for individuals with LFS. However, very little has been published on the psychosocial impact of these screening protocols. The goals of this study are to determine how participation in screening impacts individuals psychosocially, to examine the benefits and drawbacks of screening, and to evaluate possible barriers to continued screening. This qualitative study consists of phone interviews with 20 individuals that took part in an LFS screening program at M.D. Anderson Cancer Center. Data analysis showed that benefits of screening include early detection, peace of mind, centralized screening, knowledge providing power, and screening making LFS seem more livable. Perceived drawbacks included logistical issues, difficulty navigating the system, screening being draining, and significant negative emotional reactions such as anxiety, fear, and skepticism. Regardless of the emotions that were present, 100% of participants plan on continuing screening in the program. Our data indicates that the perceived benefits of screening outweigh the drawbacks of screening. Individuals in this screening program appear to have improved psychosocial well-being because of their access to the screening program.

Advisory Committee:

- Louise Strong, MD Chair
- Martha Askins, Ph.D.
- Jasmina Bojadzieva, MS
- Ralf Krahe, Ph.D
- Sarah Noblin, MS, CGC
- Susan Peterson, Ph.D. MPH