Li-Fraumeni Syndrome Registry Study

Why is this study being done?

The purpose of the Li-Fraumeni Syndrome (LFS) registry study is to collect information on personal cancer history, family history, and bank specimens from patients and family members with Li-Fraumeni syndrome. The registry aims to create a repository of data and specimens that are made available for researchers who are working to further understand the syndrome and to develop prevention, screening, and treatment recommendations. In addition, the registry provides participants the option to be notified about future research studies that may be of interest to them and their families.

Who can participate in this study?

All individuals with Li-Fraumeni Syndrome, or are part of a family with LFS, may be eligible to participate in the study.

What is involved in participating?

Participation involves:

- Questionnaire about personal and family history
- Donate a blood or saliva sample (optional)
- Allow collection of tissue specimen (optional)

How long is the study?

The study goal is to create a registry of LFS participants interested in contributing information about themselves and their families, in addition the study will notify interested individuals about new research opportunities. After consenting to participate in this study, you do not have to do anything active to continue to participate. You may withdraw at any time.

How can I get more information?

Contact:

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