# MISSION

OUR MISSION is to encourage, empower, and educate those living with Li-Fraumeni Syndrome by connecting them with care, resources, and others who are Living LFS.

# ENCOURAGE

We **encourage** each other through our Facebook Page & Support Groups. Families who have this condition are rare and special. Facebook gives us the power to network, share stories, ask for advice, and make friends around the world. If you are not a member of Facebook, we highly recommend that you join - if only to connect with our Facebook Page or Closed Groups! The closed Facebook Groups listed below are private and moderated by Living LFS, Inc.

- Li-Fraumeni Syndrome Support Group
- Li-Fraumeni Syndrome Friends And Family

# EMPOWER

We **empower** those Living LFS to connect by facilitating regional support group meetings and through our online community, helping them share their stories and experiences with LFS.

# EDUCATE

We **educate** about LFS through our website. We raise awareness of Li-Fraumeni Syndrome as well as bridge the gap between patients and the medical community.

FOLLOW LIVING LFS ON FACEBOOK AND TWITTER

Living LFS, Inc.
P.O. Box 1101
O'Fallon, IL 62269
1-844-LFS-CALL
hello@LivingLFS.org
www.LivingLFS.org

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## LIVING WITH LI-FRAUMENI SYNDROME

Li-Fraumeni Syndrome (LFS) is linked to a mutation in the TP53 tumor suppressor gene. There are many types of TP53 mutations. People with this mutation have a higher risk of developing cancer over their lifetime. LFS affects each individual differently, even within the same family. Some families with LFS have higher rates of cancer incidence, while others do not.

### WHO HAS LFS?

While Li-Fraumeni Syndrome does not affect one particular age, gender, or race, half of LFS cancers develop in children. LFS is usually passed from parent to child, but it can result from a new (de novo) mutation as well. A parent with LFS has a 50% chance of passing the mutation along to their children.

### DO YOU HAVE LFS?

Li-Fraumeni Syndrome might be suspected if you have a personal history of multiple cancers, a family history of cancer or if certain cancers are seen in children or young adults in your family. The cancers most often seen in LFS are Adrenal, Brain, Breast, Leukemias, and Sarcomas, but LFS cancers can occur anywhere in the body.

### SHOULD YOU BE TESTED?

Getting tested for a family cancer syndrome can be a daunting decision. A genetic counselor can help you weigh the risks and benefits of being tested for the TP53 mutation. Knowing whether or not you have the mutation can help you and your providers develop a personalized screening regimen designed to detect cancer at the earliest and most treatable stages. There is no one set protocol for screening LFS cancers, but there are recommendations based on the cancers frequently seen in the syndrome.

If you test positive for the TP53 mutation, it means you have an increased risk of developing cancer. It does not mean you will get cancer during your lifetime. There are many varying degrees of LFS and many people with the mutation live long, healthy lives.

### LI-FRAUMENI SYNDROME FACTS

- 50% of LFS cancers develop before the age of 30.
- A woman with LFS has a 90% chance of developing cancer in her life, much of this risk is due to Breast Cancer.
- People with LFS can develop many cancers over their lifetime.
- LFS is a dominant trait. This means if the mutation is passed to a child, their chance of getting cancer is greater than the normal population.
- Certain childhood cancers are linked to LFS – Choroid Plexus Carcinoma (brain tumors), Sarcomas (including Osteosarcoma), and Adrenocortical tumors.
- And finally….not all people with LFS get cancer.