



Together we are LFS stronger!!

March 2017

Dear LFS patient families and friends,

While attending the events at Rare Disease Week in Washington DC earlier this month, I had a renewed appreciation for the concept of “knowledge is power” as it relates to the discovery of LFS. Because of the diligence of Drs. Fred Li and Joseph Fraumeni in the 1960s, and the continued cancer research revealing the role of the p53 tumor suppressor gene, families like us who are predisposed to developing cancers are now more empowered than ever!

My husband and I are so appreciative of both of our founding fathers’ efforts, we wanted to take advantage of the opportunity to personally thank Dr. Fraumeni for their contributions to LFS cancer research. And I am writing to *you* all because it occurred to us that you may be interested in writing a note of appreciation, as well!

If you are interested in submitting a *personal* note or letter to Dr. Fraumeni expressing sentiments of appreciation for what he has done for the LFS community, please forward no more than a couple of brief paragraphs to me at: KHiggins@LFSAssociation.org . **I will collect them through mid-April** and compile them in an attractive bound presentation. PDF or JPEG formats would be appreciated! If you would rather not identify yourself, that is fine, as well. As an example for you, this is what I plan on writing:

Dear Dr. Fraumeni,

I wanted to say “Thank you” for all of your hard work and dedication to the Li-Fraumeni syndrome and cancer research and the significance of the p53 gene mutation. Know that your work has had a tremendous impact on the lives of my family. We have lost four members from cancers, ranging in ages from their teens through their 30s. We thought that we were merely “unlucky” until we had genetic testing completed. With the knowledge that we had LFS in the family, we were able to prolong the life of one of our daughters because screenings led to early detection. She passed away at age 30 of breast cancer, but because of the LFS determination, she was able to obtain a mammogram at age 21. In 2003, at age 22, she was diagnosed with breast cancer and underwent a double mastectomy, but passed away from metastatic breast cancer at age 30. Armed with the knowledge that we were an LFS family, she was able to have two daughters that are LFS negative by having her eggs tested and only healthy embryos implanted. This was only possible due to the hard work and dedication of you and Dr. Li. Having the knowledge about our p53 mutation has helped us keep my husband healthy by doing early screenings and monitoring. Know that we are very grateful to you for your work and want you to know that your research has helped us save our family from further loss due to cancer. Knowledge is power, and with the knowledge you have shared with the world... there are many, many families like ours that are able to stay healthy. Thank you!!!

Please reach out to me with any questions at KHiggins@lfsassociation.org.

Thank you!!

Kathleen Higgins
Education and Outreach Liaison

