

LFS and our Family Losses



Kerry 1983-2014



Maureen 1984-2003



Dan 1928-1966



GiGi 1960 -1993

My name is Kathy Higgins. I have lost 4 family members to LFS. The first picture is of my daughter Kerry. She was 30 years old when she passed away in 2014. She had a recurrence of breast cancer from 2005. Without the LFS diagnosis the breast cancer would not have been detected due to her young age. She had a double mastectomy in 2006 due to precancerous cells in her breast she knew she had a 90% chance of it turning into cancer. 1% breast tissue was left in and the cancer started in that 1% due to her pregnancies and hormone driven breast cancer. She was the mother of 2 little girls ages 3 & 5. She had a loving husband of 8 years. Kerry was first diagnosed with cancer at the age of 12. She had an osteosarcoma in her thigh. She received chemo and had multiple operations on her leg. She was not diagnosed as having LFS at that time. This was 1995 and LFS was just being discussed. She had several small cancer issues over the years, skin spots on face and back. It was not until our second daughter Maureen (18 years old) also developed a major cancer in 2002 that the doctors decided it was time to look further into our family medical history. Maureen had a stage 4 adrenal cortical carcinoma before we even realized she was sick. We lost her within 4 months. Maureen had surgery and chemo but did not respond well to chemo. Upon researching our family history it was discovered that my husband's dad passed away at aged 37 (1966) from a brain tumor. My husband's sister died at age 32 (1993) of three cancers within a 2 year period. Leukemia, cervical and breast cancer.

Once the possibility of LFS was discussed Kerry was tested for LFS and was shown to be positive. Our other biological daughter Eileen (Maureen's twin) was tested and was negative. My husband was not tested until 2015 due to the presumption he was positive. He did indeed show positive for the mutation. He presented with his first cancer in the fall of 2014 with a sarcoma in his arm. It was removed and radiation was the option elected for treatment prior to surgery in February of 2015. All went well until May 2015 when another sarcoma was discovered in his thigh. That was removed but no follow-up treatment was done on the recommendation of his medical team at DFCI. We are scheduled to go back to DFCI in November for a recheck for any new cancers.

I as a wife and mother I was beside myself with grief and terrified that my husband was going to suffer the same fate as Kerry, Maureen and his dad and sister. I was feeling so helpless to stop this disease, I decided that I would become an advocate for LFS and try to raise money for research and awareness. My hope was that I would be able to help identify other families that may have had the same mindset we had, in that we were just an unlucky cancer family until our LFS diagnosis was found. Awareness with people with LFS is key to survival and many doctors do not know about LFS and are missing key signs in families that could be affected with this mutation. My goal is to go around to all the doctors and medical facilities in my surrounding area and try to get them to learn more about LFS and be a provider that can help many LFS families stay healthy. Currently we have to travel 6 hours one way just to find a doctor that is familiar with LFS and can follow a healthy protocol to be screening LFS patients for early signs of cancer. In this day and age that is not acceptable.

I traveled to California in Sept. 2016 to attend a rare patient advocacy training conference. I did that so that I could be a better more effective advocate for awareness and fundraising for the LFS community.

I can never bring back my daughters nor my father-in-law and sister-in-law but if I can identify even one family that could be saved from the heartache our family has endured it was worth it.

I also started a charity organization called Mo Songs For Kerry.org with a couple of the girls friends and my family. We host a large fundraiser every year in upstate NY. We will be having our 4th annual event on 7/29/17. We use this event to raise awareness for LFS and also to raise money for research. We also donate a portion of the proceeds to a local hospital run guest home that caters to families with loved ones in the hospital and patients that are going through long outpatient treatments and do not live locally.

We have used our event to get the local TV stations to air stories about our event and LFS. This past event in 07/16 we had 4 stories run in the local TV market. We were also interviewed by all the major newspapers within our area. This lead to a large amount of press and free publicity for LFS awareness. I am very grateful for all the support our local media has given us.

Having an LFS diagnosis is a very difficult thing to live with. You are always waiting for the other shoe to drop and you feel like the boy that cried wolf if you go in and get each lump, bump and pain examined as if it is cancer returning. It makes living a normal life more difficult but at the same time you learn to appreciate every day you are given and if you are diligent with your screenings you can live a normal life.

We cannot let living LFS cause us to not live life to its fullest. We will do our best to do just that and try to honor our girls and their memory by living life as healthy and happy as we can. We know that is how that would have wanted it. Kerry lived with LFS for 10 years and managed to get married, start a business and have 2 beautiful healthy non mutant little girls. She was carrying firewood into her house as short as 3 days before she died and was entertaining all the people in her hospital room mere hours before she passed away. She did indeed live life to the fullest even with such a tremendous burden on her mind. I am very proud to be the mother of these two special ladies and I hope that I can make them proud of me with my efforts to make a difference. I will be a warrior for my husband and do everything I can to see that he is screened carefully and is treated right away if any signs of cancer appears.

I am very grateful for the Living LFS. org website where we can connect with other families going through similar problems and we are all stronger if we support one another and share our trials and tribulations as well as our joys of negative test results , positive treatment outcomes, etc. Before discovering the website we did not know a single LFS family.

Hugs and prayers to all of you out there dealing with LFS. We are stronger together !