

# History of the National Leiomyosarcoma Foundation (NLMSF)

The first **founding members** of the Foundation: **Edmund** and **Nancy Hoag**, **Harry** and **Diana Froling**, **Donna** and **Joe Fischer**, **Ken** and **Karen Gibson**.

These families were dedicated and committed to the mission of building support for the LMS patient/family Community.

**Harry** and **Diana** were inspirations to the LMS ACOR online support group, and appreciated their guidance and help. From all this, the Foundation was born and incorporated in 2001.

**Nancy Hoag** made the signature purple and green ribbons, and her family helped with mailing information to patients, as well as helping her make the ribbons.

**Karen Gibson** coordinated the first Hugfest events, bringing patients and their families together to support one another in Pennsylvania. At the first Hugfest, **Edmund Hoag** spoke of creating a foundation to raise awareness and funding for Leiomyosarcoma research.

The Hugfest attendees were all enthused to support this initiative. The Foundation was formed by the support and commitment by the LMS Community. **Edmund** and **Nancy** proceeded to secure the needed funding and the first check for LMS research was given to the Research Community.

**Karen Gibson** (treasurer and secretary of the foundation) and **Lynda Hendrix**, an LMS patient, created the LMS Quilt to honor patients, and for a hopeful display at the Washington DC mall. Two quilts were created from mailed quilt squares received from across the country.

***"The National LMS Foundation was the first to galvanize patients and researchers for advocacy, support, and education for the LMS Community in 2001 and the first to bring together researchers from around the world to privately fund LMS Research in the search for a cure"***

\* \* \* \* \*

★ ***In 2016 the NLMSF Was Successful with Congressional Approval for a National LMS Awareness Day -July 15.***

- ★ The NLMSF FB group began just before 2010, with eventually 5000 members.
- ★ In 2013 the NLMSF FB support group suddenly was taken down without notification. But in 2014 it was reinstated by new Board Members.
- ★ The NLMSF continues to serve the LMS Community to this day, through the collaborative compassion and good will of Board Members and Volunteers - patients and caregivers all

\* \* \* \* \*

Thank you for joining the NLMSF FB Support Group  
to build a strong LMS Community of Caring and Sharing!

Join the NLMSF as an Ambassador for Community  
Awareness of Leiomyosarcoma. Spreading the  
word is important for community support for the  
much needed LMS-specific research.

<https://nlmsf.org/get-involved-2/>

Sarcoma remains the least funded of all cancers for research.

*Grateful to you all - Annie Achee | Honoring the LMS Community | (President NLSMF since 2015)*