



2017 IN REVIEW - LOOKING FORWARD TO 2018

The National Leiomyosarcoma Foundation had another productive year in 2017:

- LMS Research Project with MD Anderson Cancer Center funded by the NLMSF/
- The Rare Cancer Research Foundation and the NLMSF forged a collaborate “ partnership to participate in the Cancer Cell Line Project at the Broad Institute of MIT/Harvard – to collect tumor tissue to grow cell lines for testing and data generation for global research access to help advance research initiatives.
- Invitation by Dr. George Demetri, Head of the Sarcoma Center at Dana Farber Cancer Institute, to participate in their annual Sarcoma Conference.
- The NLMSF’s Medical Advisory Committee expanded to include Dr. Jonathan Fletcher, Dana Farber Cancer Institute, MA, and Dr. Sujana Movva, Fox Chase Cancer Center, PA, and Dr. William Tap, Memorial Sloan Kettering, NY.
- 3 patient-caregiver education symposia were held at:
 - Fox Chase Cancer Center, PA
 - Fred Hutchinson Cancer Center, WA
 - Moffitt Cancer Center, FL
- The Foundation’s three websites were brought on line for new and refreshed information assistance for patients and family caregivers – specifically offering guidance on a new diagnosis, patient treatment navigation. And what to consider in next steps after treatment is completed.
- Sarcoma Centers of Excellence updates for the website, along with financial assistance resource information updates, research news, clinical trials and research articles (in the leiomyosarcoma.info website).
- Monthly LMS Live Connect patient – family telecon connections for one on one conversations to enhance peer support.
- The NLKMSF Connect with a Clinician Program – is an opportunity for patients to ask general medical questions (not case specific) about side effects management, imaging study information, to name a few examples. Volunteer research clinicians are available to answer the general questions posed through FB or by contacting annieachee@aol.com
- The NLMSF Community Outreach Ambassador program continues, having launched in 2016. Volunteers continue to be welcomed to join om building community awareness of the disease. Ambassador Tool Kits are available.

- CURE Magazine articles have been written and submitted by the Foundation, posted periodically online, and also forwarded to OncNursesNews.

WORKING FOR YOU IN 2018:

GOALS -

- **Launch the National Leiomyosarcoma Foundation's International LMS Research Roundtable with a collaborative partnership at the request of Sarcoma Patient EuroNet (SPAEN) to join the Foundation in this global initiative to advance investigational research for LMS/uLMS.**
- **LMS Community Message Board – connecting the Roundtable with patients – to provide an opportunity for patient perspectives to be communicated to the researchers, to help shape the one day Research Think Tank agendas for the future.**
- **The LMS Cancer Support Community – collaboration to bring an LMS -specific hot line for patients and family caregivers to speak to trained social workers to obtain assistance.**
- **Three Research Projects to support through the gracious donations of supporters of the Foundation:**
 - **SARC-SPORE research project for new biologically-related clinical trials in sarcoma. An evaluation of patient outcomes through a multidisciplinary approach in patient response assessment to current treatment therapies. Data generated from this will help shape future research design.**
 - **Anti PD1 / TP53 investigational research with LMS cell lines and PDX models for targeted tumor signatures – investigation of Pembrolizumab and Opdivo.**
 - **Development of non-invasive diagnostic assay for highly accurate pre-operative distinction between uLMS and LMS – detection of circulating tumor DNA - ctDNA For LMS patients. Liquid biopsy testing based on analysis of tumor-associated genetic aberrations in circulating tumor DNA (ctDNA) in plasma .**
- **SARCOMA COALITION COLLABORATION - Membership of the Foundation - Steering Committee involvement in the planning of the Consortium with SARC CEO and Rein In Sarcoma Foundation.**
- **Patient-Caregiver Education symposia scheduled:**
 - **International Sarcoma Symposium in Toronto (NLMSF participation)**
 - **May Clinic, MN**
 - **Hillman Cancer Center, PA**
 - **Knight Cancer Institute. OR NLMSF participation)**
 - **Sarcoma Alliance Sarcoma Exchange, GA (NLMSF participation)**