National LeioMyoSarcoma Foundation

Reaching For The Cure - Together

NLMSF

2016 ACCOUNTABILITY REPORT

"LOOKING BACK on 2016. . . .LOOKING FORWARD in 2017"

The National Leiomyosarcoma Foundation continues to strengthen its focus on patient/family/caregiver education, resource support and advocacy. Emphasis on supporting Leiomyosarcoma researchers is of paramount importance to the Foundation. Incentivizing young researchers to continue interest in LMS research is an important aspect of the overall research funding efforts of the Foundation.

Through the Foundation's participation at many scientific conferences and meetings throughout the year, knowledge of current cutting edge research efforts is obtained and shared with patients and their families to enable them to be well informed. This information allows patients/families/caregivers to know what questions to ask during oncology appointments, for strong patient/family self-advocacy with the medical care team.

The Foundation working for YOU in 2016 and what is in store for 2017:

1. The Foundation participated in the Dana Farber Cancer Institute's Annual Sarcoma Conference at the invitation of Dr. George Demetri, Head of the Sarcoma Center. The Foundation held a Patient/Family/Caregiver LMS Education Symposium in collaboration with MD Anderson Sarcoma Center, Houston,TX, with Dr. Vind Ravi, and a symposium in collaboration with the Siteman Cancer Center/Barnes& Jewish Hospital, St. Louis, MO with Dr. Brian Van Tine.

2. In January, 2017, the following renowned researchers have joined the Foundation Medical Advisory Committee: Dr. Jonathan Fletcher, Dana Farber Cancer Institute, Boston, MA; Dr. Sujana Movva, Fox Chase Cancer Center, Philadelphia, PA, and Dr. William Tap, Memorial Sloan Kettering, New York.

3. As of December, 2016, the Foundation welcomed four more esteemed research oncologists to the NLMSF Medical Advisory Committee: Dr. Robert Maki, Monter Cancer Center, Long island, NY; and Dr. Scott H. Okuno, Mayo Clinic, Rochester, MN. Dr. Arun Singh, UCL/Ronald Reagan Medical Center, and Dr. Sujana Movva, of the Fox Chase Cancer Center. Patient/Family Education Symposia are planned for these centers.

4. Coordinated with Senator Debbie. Stabenow's office (D-MI) to bring about the **2016 National Leiomyosarcoma Day** through Congressional approval. Efforts to obtain Congressional approval in 2017 for a National Leiomyosarcoma Day are currently underway.

5. The Foundation helped **fund two LMS specific research projects** this year, plus an impending Sarcoma Alliance through Research Collaboration / SPORE Research project. These projects Hold promise of breakthrough research to advance treatment options, enhancing survivorship.

6. The Foundation received funding support for the NLMSF Patient-Family Education Symposiums held at major sarcoma centers throughout the United States. In 2016, programs at MD Anderson Sarcoma Center in Houston, TX, and the Siteman Cancer Center/Barnes and Jewish Hospital in St. Louis, MO were well attended and well received by patients and their families/caregivers.

   NOTE: The tax deductible donations received by the Foundation are directed to LMS research projects, reviewed and approved by the Foundation's Medical Advisory Committee. Visit www.nlmsf.org to become acquainted with the Medical Advisory Committee comprised of world renowned clinicians. New additions to the Medical Advisory Committee Members have joined in

7. **BI Annual Symposiums starting in 2017 include:**
   - **UCLA/Ronald Reagan Medical Center, Santa Monica, CA, with Dr. Arun Singh** and his Sarcoma team;
   - **Fox Chase Cancer Center in Philadelphia, PA with Dr. Sonja Movva** and her sarcoma Team. Dr. Movva has at least 2 LMS specific clinical trials currently underway.
   - **Fred Hutchinson Cancer Center, Seattle, WA and Portland, OR with Dr. Seth Pollack,** and his sarcoma team, through collaboration with the Northwest Sarcoma Foundation and Seattle Cancer Care. Dr. Pollack has been involved in T-Cell therapy research and clinical trials.
   - **Moffitt Cancer Center, Tampa, FL with Dr. Mihaela Druta** and her sarcoma team. Dr. Druta is currently involved in LMS specific clinical trials and studies.
   - **Monter Cancer Center, Northwell Health with Dr. Robert Maki, Sarcoma Center**, New Hyde Park, NY. Dr. Maki is a world renowned research oncologist and an international immunology expert.

8. The Foundation has **redesigned its website as a PATIENT COMPASS addressing what to do, what to ask, who on the care team to ask - if someone is newly diagnosed; for patient treatment navigation; after treatment -** with specific sections devoted to patient resources available. The website contains helpful video presentations from world renowned research clinicians, and more. Visit: www.nlmsf.org.
   The website is continuously updated with information on new and ongoing clinical trials, research news, and pertinent medical articles. A list of Sarcoma treatment centers throughout the US and abroad, with updated and accurate contact information, as well as financial assistance resource

organizations, lodging at treatment centers, house cleaning, meal preparation and more. There is also a caregiver's corner with helpful information.

9. THE FOUNDATION HAS BEEN INVITED TO BECOME THE NEW STEWARD OF THE LEIOMYOSARCOM.INFO WEBSITE, to be linked to the Foundation website: www.nlmsf.org. The linked website will be reviewed for necessary updates this year, but also archived.

10. The Foundation has launched a **monthly LMS LIVE CONNECT** - PATIENT to PATIENT telecon connection providing patients and families the opportunity to converse with one another, to build hope and strength, inspire and support one another. If you wish to participate, please email annieachee@aol.com.

11. A **new FaceBook Group** has opened, as well as a **patient/caregiver blog** capability through the Foundation's website, with global reach out as a result. Click on the Home page for access.

12. The Foundation has launched a **Facebook NLMSF CONNECT WITH A CLINICIAN PROGRAM – Patient to Clinician Access - Question and Answer (Q & A)** providing a communication support connection for general questions and answers only, and not meant to take the place of the patients oncology care team.
Renowned clinicians representing pathology, immunology, research oncology, psychosocial issues, are available to patients for this Q & A opportunity. Visit www.nlmsf.org to see who has volunteered for this program and how you can best access them through the NLMSF FaceBook.

13. The Foundation generates weekly **E-Bulletins**, providing informative briefs on new research information, Caregiver support articles, general well being tips, and more. Let us know if you would like to be added to the email list to receive the NLMSF weekly E Bulletins.

14. A **Foundation Community Ambassador Program** began in April of 2016 - to encourage patients, families, friends, co workers to reach out and build awareness at schools, churches, club affiliations, etc. and encourage support for the much needed LMS research. Email annieachee@aol.com or call 303 783—0924 if you would like to volunteer to represent the Foundation as a Community Ambassador where you live. A Volunteer Community Outreach Foundation Ambassador Tool Kit can also be requested as a helpful idea resource to support Ambassadors.

15. The Foundation has collaborated with CURE MAGAZINE, writing articles that are posted periodically on line, and also are forwarded to OncNursesNews. A 2016 press release regarding