# LeiomyoSarcoma
SUPPORT & DIRECT RESEARCH FOUNDATION
~~WISHING~~ WORKING FOR THE CURE

www.lmsdr.org

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Originating in 2006, the (Leiomyosarcoma Support and Direct Research) LMSDR foundation is an all-volunteer staff of patients and caregivers, who are passionate about supporting others and helping researchers to find treatments that will work.

**LMSDR FOUNDED**

Achieved charitable 501(c)(3) status

2006 – 2017: Over 500 **LMS tumor paraffin blocks and patient histories**, collected

2006 $40,000 Research Awarded

2007 $25,000 Research Awarded

2008 $50,000 Research Awarded

2009 $75,000 Research Awarded

2010 $25,000 Research Awarded

2011 $50,000 Research Awarded

2012

2013 $50,000 Research Awarded — Colorado Conference

2014 $110,000 Research Awarded — San Francisco Conference

2015 $110,000 Research Awarded

2016 $125,000 Research Awarded — New York Conference

2017 $132,000 Research Awarded

2018 $266,000 Research Awarded — Hawaii Conference

2019 $147,000 Research Awarded

2020 $250,000 Research Awarded — Miami Conference

2021 $250,000 Research Awarded

2022 $200,000 Research Awarded

2023 $100,000 Research Award — London Conference

2024 $75,000 Research Awarded — Los Angeles Conference

**2025/26** ***£1M CAR T-Cell prospective clinical trial***




**LMSeAlerts** News-letter begins (3,800 Subscribers)

**Anti-Morcellation Campaign** begins– campaign to ban uterine morcellation. Result: FDA ordered a black box warning on all morcellation devices and restricted its use greatly

Joined RARE Foundation Alliance (collaborate with other nonprofits)

Launched an **independent LMS Patient Registry** in collaboration with the Coordination of Rare Diseases at Stanford (CoRDS). Helps researchers study LMS and identify potential participants for clinical trials.

**Patient Advocate** Training webinars and advocate projects

**Blood donation drive** for studying LMS circulating tumour DNA to find a diagnostic tool to distinguish uLMS tumors vs. benign fibroids preoperatively.

Initiated **LMS Awareness Day– July 15th**

Joined Sarcoma Coalition– join with other sarcoma foundations

Partnered with **Rare Cancer Research Foundation's (RCRF) Cell Line Project** to provide live fresh LMS tissue donations, for the purpose of starting new LMS living cell lines for researchers

**Long Term Thrivers Blog** begins– gives hope to newly diagnosed

**New Member Chat** (Monthly)- Connects long term survivors to new ones

Became a member of Sarcoma Patients EuroNet association

LMS Cruise

***2020: It Happened to Me!* Campaign**– collected and sent over 100 patients' stories and letters to US Government requesting LMS research and patient education be included in the Uterine Fibroid Research and Education Act of 2020.

Virtual webinars begin

***2021: Kicking the Hornets' Nest*** by Kyle Floyd—co produced by LMSDR. Award winning documentary– helping to spread awareness and stop the tragedies of uterine morcellation.

**Partnering with LMS Research UK–** A new UK charity supporting research and patient advocacy in the UK.

Partnership with Broad Institute's ***COUNT ME IN Project***, helping LMS patients to donate their rare tumor tissue, blood, saliva and their LMS histories for researchers to study.

Star denotes patient education Conference

# Awarded over $5,000,000 for LMS Research in the last 20 years

**2006:** ***Microarray analysis of LMS from the paraffin tumor blocks donated by LMS patients worldwide*** ($40,000: Dr. M. van de Rijn, Stanford)

**2007:** ***"Let-7 repression leads to HMGA2 overexpression in uterine leiomyosarcoma."*** ($25,000: Dr. E. Hernando, New York University School of Medicine)

**2008:** ***"Discovery of Molecular Subtypes in Leiomyosarcoma through Integrated Molecular Profiling."*** ($50,000: Drs. M. van de Rijn (Stanford), C.D. Fletcher (Dana Farber) and Coreless (Washington State University))

**2009:** ***"Prognostic Significance of Macrophage Infiltration in Leiomyosarcomas."*** ($50,000: Dr. M. van de Rijn, Stanford)

**2009 and 2010:** ***"A Role for BRCA1 in Uterine Leiomyosarcoma."*** (Total $50,000: Dr. S. Orsulic, Cedars Sinai)

**2011:** ***ROR2 is a Novel Prognostic Biomarker and a Potential Therapeutic Target in Leiomyosarcoma.***
- ***The Effect of Mir-17-92 Dysregulation in Leiomyosarcoma-Genesis.***
- ***Antibody Therapy Targeting the CD47 Protein is Effective in a Model of Aggressive Metastatic Leiomyosarcoma***
- ***Flipping the Script on Macrophages in Leiomyosarcoma***
- ***CFS1 Expression in Nongynological Leiomyosarcoma is Associated with Increased Tumor Angiogenesis***

($50,000 awarded jointly by LMSDR and the Liddy Shriver Sarcoma Initiative: Dr. M. van de Rijn, Stanford)

**2013:** ***The Study of Three Therapeutic Targets in Leiomyosarcoma***
- ***Engineered SIRPa Variants as Immunotherapeutic Adjuvants to Anticancer Antibodies.***
- ***Comparative Gene Expression Profiling of Benign and Malignant Lesions Reveals Candidate Therapeutic Compounds for Leiomyosarcoma***

($50,000 awarded along with $100,000 from the Liddy Shriver Sarcoma Initiative: Dr. M. van de Rijn, Stanford)

**2014 and 2015:** ***"Using Circulating Tumor DNA as a Measure of Tumor Load and Response to Therapy."***
- ***Clinically Relevant Molecular Subtypes in Leiomyosarcoma.***
- ***A Role for Versican in the Development of Leiomyosarcoma.***
- ***Progressive Loss of Myogenic Differentiation in Leiomyosarcoma Has Prognostic Value.***

($110,000 in 2014 and $110,000 in 2015: Dr. M. van de Rijn, Stanford)

**2016:** ***"Maximizing Therapeutic Response in LMS"*** ($125,000: Drs. C.D. Fletcher (Dana Farber), M. van de Rijn (Stanford), F. Chibon (France's Bergonie Institute), S. Bauer (West German Cancer Center) and D. Langenau (Massachusetts General Hospital.) Co-funded collaboratively with the Liddy Shriver Foundation and National Leiomyosarcoma Foundation)

**2017:** ***ART Inhibition in ALT Positive Leiomyosarcoma and Osteosarcoma.*** $2,000: Dr G. Cote, Massachusetts, funded by the Lissy McMahon Memorial fund.

***2017: ROR2 and a Potential Target in LMS*** ($40,000 Dr. M. van de Rijn, Stanford)

**2017, 2018 and 2020:** ***"Using Circulating Tumor DNA as a Measure of Tumor Load and Response to Therapy."*** ($90,000 in 2017, $140,000 in 2018 and $100,000 in 2020: Dr. M. van de Rijn, Stanford)

**2018 and 2019***: "Exploring LMS Functional Genomics to Identify Disease Specific Vulnerabilities."* ($42,000 in 2018 and $47,000 in 2019: Dr M. Hemming, Dana Farber)

**2018:** ***"Identification of a Novel Treatment Strategy for Uterine Leiomyosarcoma in Genotype Defined Patient Population."*** ($74,000: Dr T. Omelchenko, Sloan Kettering)

**2018:** ***"Kicking the Hornets Nest."*** ($10,000: K. Floyd for his documentary, documenting the history of uterine morcellation and the consequences for women with leiomyosarcoma)

**2019 and 2020:** ***New targets for LMS, including the role of TP53, pten, p13K and mTOR***. ($100,000 in 2019 and £150,000 in 2020: SARC – Sarcoma Alliance for Research Collaboration)

**2021:** ***"Identifying Biomarkers Predictive of Benefit to Rucaparib and Nivolumab in Patients with Advanced Leiomyosarcoma."*** ($100,000: Dr. S. Movva, Sloan Kettering)

**2021:** ***"Metabolic Reprogramming in Leiomyosarcoma."*** ($100.000: Dr. J. Przybyl, Stanford)

**2021: "Biological pathways&immune landscape associated with Gem/Tax therapy resistance and response in LMS."** ($50,000, Debbie Foley Grant: Dr. P. Huang, Royal Marsden UK, and Dr. J. Przbyl, Stanford.

**2022:** ***Development of an Immune Biomarker for Metastatic Disease in Retroperitoneal LMS*** ($100,000: Dr. W. Tseng, City of Hope Duarte)

**2022:** ***Novel Treatments of Leiomyosarcoma, using validated LMS cell lines to check the ability of best FOXM1 inhibitor either ± PROTACs, ETC-168 or Doxorubicin to retard growth of LMS*** ($100,000: Dr. H. P. Koeffler, Cedars Sinai)

**2023:** ***Starting from an N of 1: Integrating genomic, analytic and functional analyses to establish a real-time treatment discovery and validation platform*** ($50,000: Dr J. A. Martignetti, Mount Sinai)

**2023:** ***Liquid biopsy for uterine leiomyosarcoma*** ($50,000 awarded to Dr. J. Przbyl, McGill University in partnership with the Sarcoma Alliance for Research through Collaboration (SARC) Catalyst program)

***2023: Strategic Awareness in Sarcoma Science (SASS) Conference Sponsor*** ($10,000)- 115 sarcoma researchers met in partnership with the National Cancer Institute to define new research projects for sarcomas.

***2024: Distribution of Novel Human Macrophage Subsets in Leiomyosarcoma (building on previous macrophage work in Dr. Matt van de Rijn's lab)*** ($25,000: Dr Magda Matusiak, Stanford University Med. Ctr).

***2024: Targetable Addictions Associated with Epigenetic Reprogramming of Leiomyosarcoma*** ($50,000: Dr. H. Phillip Koeffler, Cedars Sinai).

***2025: Circulating tumor DNA monitoring for long-term surveillance of leiomyosarcoma patients*** ($47,500 Dr. J. Przbyl (McGill)

***2025: A phase I/II study of Pexidartinib with Pembrolizumab for locally advanced or metastatic LMS*** ($25,000 Dr E. Moding and Dr M. Zhou)

***2025: Methods to study patient samples and identify the neoantigens unique to LMS*** ($100,000 T. Omelchenko, Rockerfeller University)

***2025/26: CAR T-Cell clinical trial*** ($1M Dr G.Allen, K.Roybal, B.Schulte,