

The purpose of this guide is to help you find information and support on mastocytosis. This guide provides links and references to reliable and current information sources for patients, families, and caregivers.

Many of these materials are available to purchase through online resources, or to borrow at your public library.

Brochures and Fact Sheets

- **The Mastocytosis Society, Inc.**

<http://tmsforacure.org/welcome.php>

This site provides research, education, and advocacy for patients, families, caregivers, and physicians.

- **Leukemia & Lymphoma Society. Understanding Lab and Imaging Tests.**

Available online at:

http://www.lls.org/sites/default/files/file_assets/PS41_UnderstandingLabandImagingTests_5_17_reprint.pdf

Audiovisual Resources

- **MPN Advocacy & Education International. Interview with Dr. Marie Huong Nguyen, University of Michigan, MPC Researcher/Clinician.**

Available at:

<http://mpnadvocacy.com/2016/02/ann-brazeau-interviews-dr-nguyen>

- **MPN Education Foundation. MPN Video Library.**

Available at:

<https://mpninfo.org/category/video-library/>

Web Resources

- **American Academy of Allergy Asthma & Immunology**

<https://www.aaaai.org/conditions-and-treatments/related-conditions/systemic-mastocytosis>

This site provides information on systemic mastocytosis, including an overview, symptoms, diagnosis, and treatment.

- **Cancer.Net: Mastocytosis** (provided by the American Society for Clinical Oncology)

<https://www.cancer.net/cancer-types/mastocytosis/view-all>

This site provides an overview and other information such as statistics, symptoms, diagnosis, stages, treatment option, latest research, and coping with side effects.

- **Genetic and Rare Diseases (GARD) Information Center**

<https://rarediseases.info.nih.gov/gard/6987/mastocytosis/resources/8>

Provides information on mastocytosis, including topics such as symptoms, tests, diagnosis, drugs, statistics, news, and research.

- **National Organization for Rare Disorders (NORD)**

<https://rarediseases.org/>

This site includes information on Mastocytosis as well as causes, treatment therapies, and related disorders.

- **Together with Systemic Mastocytosis**

<http://systemicmastocytosis.com>

This site provides information on systemic mastocytosis as well as patient stories and expert views.

University of Michigan Resources

- University of Michigan Rogel Cancer Center Blog article in **mCancer Talk**. **Myeloproliferative Neoplasms: A Collection of Rare Blood Cancers**.
<http://uofmhealthblogs.org/cancer/living-with-cancer-2/myeloproliferative-neoplasms/27467>
- University of Michigan Rogel Cancer Center Clinical Trials for myeloproliferative neoplasms. Our **MPN and Systemic Mastocytosis Clinic** has a number of studies underway. Most are available only to our patients. We have extensive experience in selecting the right trial for each person.
<https://www.rogelcancercenter.org/bone-marrow-transplant/clinical-trials>

Support Groups and Online Communities

- **RareConnect.org: Mastocytosis and Mast Cell Activation Disorders Online Community**
This is an email discussion group for rare disease patients and families. To subscribe, go to:
<https://rareconnect.org/en/community/mastocytosis-and-mast-cell-activation-disorders>

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