



Don't be in the dark about desmoid tumors

UNDERSTAND WHAT'S NEXT

Desmoid tumors are rare, and being diagnosed with one can leave you with more questions than answers. Understanding the nature of this disease and the unpredictable ways desmoid tumors and their “tendrill-like” growths can affect your body is important.

Care approaches are always evolving. To stay up to date on the latest treatments, you can consult the [NCCN Guidelines for Patients®](#) which are updated frequently with the latest recommendations for desmoid tumor care.¹

Use these questions to help inform your conversation with your doctor and get the most out of your next appointment.

If you **may have a desmoid tumor** or **have been diagnosed** with a desmoid tumor, consider asking:

- What is a desmoid tumor?
- How will a desmoid tumor impact my health?
- What are the signs and symptoms of desmoid tumors?
- How do you test for a desmoid tumor? Can a biopsy determine if I have a desmoid tumor?
- What kinds of specialists should I consult with?
- Are there hospitals or health centers that specialize in desmoid tumor treatment?

or

If you want to know more about **desmoid tumor management**, consider asking:

- How will I know if my tumor is progressing?*
- What symptoms should I be aware of and how can I track them?
- What potential treatment options are available to me? What are the risks and benefits associated with each of these options?
- What are the risks and benefits of surgery? Can my desmoid tumor come back after it's been removed?
- What treatments do desmoid tumor experts recommend?
- If I experience potential side effects during treatment, are there ways to help manage them?

*Progression is a word used to describe how a medical condition advances, or gets worse.²

WANT MORE INFORMATION?



**Desmoid Tumor Research
Foundation (DTRF)**
dtrf.org



Global Genes
globalgenes.org



**NCCN Guidelines for Patients®
Soft Tissue Sarcoma**
nccn.org



**National Organization
for Rare Disorders (NORD)**
rarediseases.org



**Northwest Sarcoma
Foundation**
nwsarcoma.org



Rein in Sarcoma
reininsarcoma.org



**Sarcoma Alliance for Research
through Collaboration (SARC)**
sarctrials.org



**Sarcoma Foundation
of America**
curesarcoma.org

Find a list of [sarcoma centers](#) on the website for Sarcoma Alliance for Research through Collaboration (SARC), a non-profit organization.

SpringWorks Therapeutics, Inc. is providing these links to help patients find more information about desmoid tumors, but inclusion on this list does not represent an endorsement or a recommendation from SpringWorks for any group or organization. The organizations listed are independent of SpringWorks Therapeutics.

NOTES

To learn more, visit our website at DESMOIDTHUMORS.COM

References: **1.** Referenced with permission from the NCCN Guidelines for Patients® for Soft Tissue Sarcoma 2024. © National Comprehensive Cancer Network, Inc. 2024. All rights reserved. Accessed June 18, 2024. To view the most recent and complete version of the NCCN Guidelines for Patients, go online to NCCN.org/patientguidelines. NCCN makes no warranties of any kind whatsoever regarding their content, use, or application, and disclaims any responsibility for their application or use in any way. **2.** NCI (National Cancer Institute). Dictionary of cancer terms: progression. Accessed June 18, 2024. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/progression>