



SpringWorks Therapeutics and Jewelry Designer Jennifer Fisher Team Up to Encourage People with Desmoid Tumors to Take Action Before Their Tumor Takes Over

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- Educational campaign aims to raise awareness and drive conversation about desmoid tumors, the devastating impact they have on patients' lives -

, /PRNewswire/ -- SpringWorks Therapeutics, Inc. (Nasdaq: SWTX), a commercial-stage biopharmaceutical company focused on severe rare diseases and cancer, and Jennifer Fisher, jewelry designer and desmoid tumor patient advocate, are collaborating to increase understanding of desmoid tumors as well as to encourage patients to find a specialist, like an oncologist with experience treating desmoid tumors who can discuss available treatment options to manage their desmoid tumor.



Desmoid tumors are aggressive and invasive tumors that can arise in any part of the body.^{1,2} Their tendril-like growths can wrap around nearby tissue and compress vital organs and nerves.²⁻⁴ This can cause severe and chronic pain, loss of function, reduced mobility, disfigurement, and anxiety, all of which can profoundly diminish a person's health and quality of life.^{1-3,5-7} Desmoid tumors are most commonly diagnosed in patients between the ages of 20 and 44 years and have a two-to-three times higher prevalence in females.⁸⁻⁹

"I was diagnosed with a desmoid tumor on my chest wall when I was 30 years old. I had so many questions, no answers, and didn't know what to expect for my future," said Jennifer. "Having a desmoid tumor was an emotional journey for me but it also shaped who I am today. I am passionate about sharing my story and proud to be working with SpringWorks to encourage others to seek expert care for their desmoid tumor and not let the physical pain from these tumors rob them of their vitality."

At the time of Jennifer's diagnosis, there were no approved treatments for desmoid tumors. Initially her doctors recommended that Jennifer have the tumor surgically removed, which would have taken half of her left chest wall with the possibility of permanently losing mobility in her arm.

"Since desmoid tumors have a high rate of recurrence after surgery, treatment guidelines now recommend systemic therapies for most desmoid tumors that are growing and/or symptomatic," stated Dr. Alessandra Maleddu, Sarcoma Specialist, University of Colorado. "As science continues to evolve, it's important for patients with desmoid tumors to be aware of the latest treatments available and to talk to their doctor about non-surgical options."

People living with a desmoid tumor should closely track how their symptoms are impacting daily life to gauge if their desmoid tumor could be progressing. Having increased pain or not being able to keep up with everyday activities could be signs that it is time to take action. Individuals should speak to a specialist, like an oncologist with experience treating desmoid tumors, and advocate to find the best approach for treatment.¹⁰

"Our commitment to the desmoid tumor community runs deep, and we are pleased that Jennifer is sharing her powerful story to raise awareness about these devastating tumors and encourage patients to take action to manage their desmoid tumor," said Bhavesh Ashar, Chief Commercial Officer at SpringWorks Therapeutics. "Jennifer's experience shines a light on the many struggles that patients with desmoid tumors face and underscores the importance of patients advocating for themselves and finding the right care team to determine the best approach for their treatment."

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About Desmoid Tumors

Desmoid tumors are rare, aggressive, locally invasive tumors of the soft tissues that can be serious, debilitating, and, in rare cases when vital structures are impacted, life-threatening.^{1,2}

Desmoid tumors are most commonly diagnosed in patients between the ages of 20 and 44 years, with a two-to-three times higher prevalence in females.^{8,9} It is estimated that there are 1,000-1,650 new cases diagnosed per year in the United States.^{8,11,12}

Although they do not metastasize, desmoid tumors can be associated with recurrence rates of up to 77% after surgical resection.^{9,13} Desmoid tumor experts and treatment guidelines now recommend systemic therapies as first-line intervention instead of surgery for most tumor locations requiring treatment.^{10,14}

About SpringWorks Therapeutics

SpringWorks is a commercial-stage biopharmaceutical company dedicated to improving the lives of patients with severe rare diseases and cancer. We developed and commercialized the first and only FDA-approved therapy for adults with progressing desmoid tumors and the first and only FDA-approved medicine for both adults and children with symptomatic neurofibromatosis type 1 associated plexiform neurofibromas (NF1-PN) not amenable to complete resection. We are also advancing a diverse portfolio of novel targeted therapy product candidates for patients with both solid tumors and hematological cancers.

For more information, visit www.springworkstx.com and follow [@SpringWorksTx](#) on X, [LinkedIn](#), [Facebook](#), [Instagram](#), and [YouTube](#).

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References

1. Sbaraglia M, Bellan E, Dei Tos AP. The 2020 WHO Classification of Soft Tissue Tumours: news and perspectives. *Pathologica*. 2021;113(2):70-84. doi:10.32074/1591-951X-213.
2. Penel N, Chibon F, Salas S. Adult desmoid tumors: biology, management and ongoing trials. *Curr Opin Oncol*. 2017;29(4):268-274. doi:10.1097/CCO.0000000000000374.
3. Constantinidou A, Scurr M, Judson I, Litchman C. Clinical presentation of desmoid tumors. In: Litchman C, ed. *Desmoid Tumors*. Springer; 2012:chap 2. Accessed August 2023. <https://www.researchgate.net/publication/226455135>. doi:10.1007/978-94-007-1685-8_2.
4. Joglekar SB, Rose PS, Sim F, Okuno S, Petersen I. Current perspectives on desmoid tumors: the Mayo Clinic approach. *Cancers (Basel)*. 2011;3(3):3143-3155. doi:10.3390/cancers3033143.
5. Husson O, Younger E, Dunlop A, et al. Desmoid fibromatosis through the patients' eyes: time to change the focus and organisation of care? *Support Care Cancer*. 2019;27(3):965-980. doi:10.1007/s00520-018-4386-8.
6. Gounder MM, Maddux L, Paty J, Atkinson TM. Prospective development of a patient-reported outcomes instrument for desmoid tumors or aggressive fibromatosis. *Cancer*. 2020;126(3):531-539. doi:10.1002/cncr.32555.
7. Bektas, M, et al. Desmoid Tumors: A Comprehensive Review. *Adv Therapeutics* 2023. doi.org/10.1007/s12325-023-02592-0.
8. van Broekhoven DLM, Grünhagen DJ, den Bakker MA, van Dalen T, Verhoef C. Time trends in the incidence and treatment of extra-abdominal and abdominal aggressive fibromatosis: a population-based study. *Ann Surg Oncol*. 2015;22(9):2817-2823. doi:10.1245/s10434-015-4632-y.
9. Skubitz KM. Biology and treatment of aggressive fibromatosis or desmoid tumor. *Mayo Clin Proc*. 2017;92(6):947-964. doi:10.1016/j.mayocp.2017.02.012.
10. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Soft Tissue Sarcoma V.2.2023. © National Comprehensive Cancer Network, Inc. 2023. All rights reserved. Accessed August 2023. To view the most recent and complete version of the guideline, go online to NCCN.org. 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.
11. Orphanet Report Series: Rare Diseases collection. Prevalence and incidence of rare diseases: bibliographic data. Number 1, January 2022. Accessed November 5, 2024. https://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf.
12. U.S. Department of Commerce. News Blog. U.S. population estimated at 332,403,650 on Jan. 1, 2022. Accessed August 2023. <https://www.commerce.gov/news/blog/2022/01/us-population-estimated-332403650-jan-1-2022#~>.
13. Easter DW, Halasz NA. Recent trends in the management of desmoid tumors. Summary of 19 cases and review of the literature. *Ann Surg*. 1989;210(6):765-769. doi:10.1097/0000658-198912000-00012.
14. Gronchi A, et al. Desmoid Tumor Working Group. The management of desmoid tumours: a joint global consensus-based guideline approach for adult and pediatric patients. *Eur J Cancer*. 2020;127:96-107. doi:10.1016/j.ejca.2019.11.013.



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