



[Click here to learn more about the 2025 DTAM logo design.](#)

Created by desmoid tumor patient: Cassandra Hernandez

PARTNER TOOLKIT



NOTE FROM LYNNE HERNANDEZ

DTRF's Executive Director

Dear Partner,

Thank you for taking part in **Desmoid Tumor Awareness Month (DTAM)** this September!

Awareness is a fundamental pillar of progress in advancing rare disease research, and ultimately improving the lives of patients. Recognition of our awareness month was initiated by desmoid tumor patients, and we champion their efforts by continuing to raise awareness each September. Sharing about Desmoid Tumor Awareness Month with your networks will directly and positively impact the future of desmoid tumor patients worldwide by shining a light on the patient experience, promoting curiosity, and ultimately broadening our reach to affect greater change.

The Desmoid Tumor Research Foundation (DTRF) values your partnership during this campaign and all year round. We hope this Partner Toolkit will make supporting DTAM as easy as possible.

Please feel free to contact us at info@dtrf.org with any questions or to let us know any unique ways you are celebrating this year.

In gratitude,

Lynne Hernandez

Executive Director



AWARENESS SPOTLIGHT

DTRF Featured in Newsweek Article:

“Research Moves Slowly.
Rare Diseases Don't—
So Patients Aren't Waiting”

[READ FULL ARTICLE](#)

SHARE WITH YOUR NETWORKS!



DTAM Awareness Tools

Official DTAM Website

Includes:

- What is a desmoid tumor?
- Ways to celebrate DTAM as a patient, caregiver, community member and/or supporter
- DTAM Resources
- Past DTAM Events

Official DTAM Hashtags:

#DesmoidAwareness
#DesmoidTumorAwarenessMonth



2025 DTAM Virtual Events:



TIFFANY BRASWELL

Desmoid Tumor Patient Advocate
Sept. 25th @ 6 PM ET
Facebook Live Event



EDUCATIONAL WEBINAR

Pregnancy and Desmoid Tumors featuring doctors from Dana Farber Cancer Institute and Brigham and Women's Hospital
Oct. 10th @ 12 PM ET
[Click here to register for webinar](#)

Support #DesmoidAwareness this month by:

- Using our [Twibbonize campaign](#) to add the Official DTAM Awareness Frame to your social media profile photos
- Sharing our patient stories posts (photos and videos)
- Attending and promoting our two DTAM Virtual Events
- Sharing DTRF desmoid tumor fact posts



DTAM Social Media

DTRF Social Accounts to Follow/Share/Tag:

Facebook: [Facebook.com/desmoid](https://www.facebook.com/desmoid)

Twitter/X: [@DTRFoundation](https://twitter.com/DTRFoundation)

Instagram: [@dtrfoundation](https://www.instagram.com/dtrfoundation)

LinkedIn: [linkedin.com/company/desmoid-tumor-research-foundation-dtrf/](https://www.linkedin.com/company/desmoid-tumor-research-foundation-dtrf/)

Social Media Sample Language

Please tag us whenever possible so that we can retweet or reshare your post!

Twitter/X

Tweet #1:

September is #DesmoidTumorAwarenessMonth!

We're proud to spread #DesmoidAwareness with @DTRFoundation. #Desmoid tumors are rare, invasive, soft tissue tumors with 5-6 new cases per 1M people each year. Get involved & find upcoming events at DTRF.org/awareness

Tweet #2:

It's #DesmoidTumorAwarenessMonth!

#Desmoid tumors arise in connective tissues. They do not metastasize but can be locally aggressive & damage surrounding tissues & vital structures as they grow. Help raise #DesmoidAwareness with @DTRFoundation at DTRF.org/awareness



Questions? Email the DTRF team at info@dtrf.org

Thank you to our DTAM
social media sponsor:





DTAM Social Media (cont.)

Other Social Media Platforms

Post #1:

September is #DesmoidTumorAwarenessMonth!

We're proud to spread #desmoidawareness with the Desmoid Tumor Research Foundation. Get involved and find upcoming events at DTRF.org/awareness.

Post #2:

#Desmoid tumors (also known as aggressive fibromatosis) are rare, invasive, soft tissue tumors with 5-6 new cases per every 1 million people each year. However, due to frequent misdiagnosis, the number of cases may be higher. For patient stories, virtual events, and more, please follow the Desmoid Tumor Research Foundation, engage, and share!

Post #3:

September is #DesmoidTumorAwarenessMonth!

The patient experience is vast and varied, and many patients' journeys can include a challenging path to diagnosis and too many questions along the way to find a treatment plan that works for them.

We're proud to spread #desmoidawareness with the Desmoid Tumor Research Foundation. Get involved and find upcoming events at DTRF.org/awareness.

For patient stories, virtual events, and more, please follow the Desmoid Tumor Research Foundation, engage, and share!

Download Social Media Graphics

CLICK HERE

to access the DTAM Partner Graphics folder, which includes:

- DTAM post social media graphics
- DTAM cover graphics for use on Facebook, Instagram, Twitter & LinkedIn
- Desmoid Tumor Awareness Month logo file (Used to show support on a website, email, etc.)



DTAM Content to Share

Newsletters/Email/Website Blurb

September is Desmoid Tumor Awareness Month!

We're proud to spread #desmoidawareness with the Desmoid Tumor Research Foundation. Get involved and find upcoming virtual events at DTRF.org/awareness.

For patient stories, virtual events, and more, be sure to follow and engage with the Desmoid Tumor Research Foundation on Facebook (Facebook.com/desmoid), Instagram (@dtrfoundation), Twitter (@DTRFoundation) and LinkedIn (linkedin.com/company/desmoid-tumor-research-foundation-dtrf-/)

Thank you for helping to raise #DesmoidAwareness!

Patient Stories in the Media

Jennifer Fisher (2025)

<https://www.elle.com/fashion/accessories/a46636853/jennifer-fisher-career-interview/>

<https://medium.com/authority-magazine/unstoppable-how-jennifer-fisher-has-redefined-success-while-navigating-society-with-a-desmoid-2f0eb0635912>

Gabe (2024)

<https://www.mlive.com/news/grand-rapids/2024/02/i-dont-let-it-affect-me-teen-with-rare-tumor-advocates-for-mental-health-awareness.html>

Dana (2024)

<https://patientworthy.com/2024/04/25/amputation-desmoid-tumor-recurrence-hope-danas-story/>

Stephanie (2023)

<https://patientworthy.com/2023/04/20/rare-community-profiles-stephanies-desmoid-tumor-journey/>



DTAM Content to Share

Amy & Jeanne (2022)

<https://patientworthy.com/2022/09/21/september-desmoid-tumor-awareness-month-amy-jeanne-pt1/>

<https://patientworthy.com/2022/09/22/september-desmoid-tumor-awareness-month-amy-jeanne-pt2/>

Increasing Desmoid Tumor Awareness, Pts. 1 & 2 (2022)

<https://patientworthy.com/2022/10/11/dr-maleddu-increases-desmoid-tumor-awareness-pt1/>

<https://patientworthy.com/2022/10/12/dr-maleddu-raises-desmoid-tumor-awareness-pt2/>

“Brave/RoarMashup” by #DesmoidSurvivor DeAnn Sorenson & Family (2020)

<https://vimeo.com/manage/videos/462777772>

Resources to Share

- 1 [DTRF First Steps Page](#)
- 2 [DTRF Diagnosis and Treatment Page](#)
- 3 [DTRF “FAQs” Page](#)
- 4 [DTRF Patient Brochure](#)
- 5 [Global Consensus Paper on Desmoid Tumor Treatment](#)
- 6 [Nirogacestat - The Pathway to Approval](#)



Thank you!

On behalf of the DTRF and patients everywhere who rely on us to advance desmoid tumor science for the promise of a better tomorrow, we thank you for your support during Desmoid Tumor Awareness Month!

