



PARTNER TOOLKIT

Dear Partner,

Thank you for taking part in Desmoid Tumor Awareness Month (DTAM) this September! The Desmoid Tumor Research Foundation team values your partnership during this campaign and all year round. We hope this Partner Toolkit will make supporting DTAM as easy as possible.

Awareness is a fundamental pillar of progress in advancing rare disease research. Your amplification of DTAM to your followers, networks, and beyond, will directly and positively impact the future of desmoid tumor patients worldwide.

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

*In gratitude,
The DTRF Team*

Official DTAM Website:

[DTRF.org/awareness](https://dtrf.org/awareness)

Includes:

- o How to get involved in and celebrate DTAM, including “**Submit your story**” form link
- o “What are desmoid tumors?” language

- o “What is Desmoid Tumor Awareness Month” language
- o “Why September?” language
- o ...and more!

Official DTAM Hashtags:

- #DesmoidAwareness
- #DesmoidTumorAwarenessMonth

Official DTRF DTAM 2023 Awareness Frame:

- Use our [Twibbon campaign](#) to add the Official DTAM Awareness Frame to social media profile photos.

Support #DesmoidAwareness by sharing DTRF’s content:

- Patient Stories Posts (photos and videos)
- Desmoid Tumor Fact Posts
- Promotions for our 2 DTAM Facebook *LIVE* Events & the Live Events themselves (*see “Special Events” section below*)
- News, Updates & Reminders About the **DTRF Together We Will Weekend and RFA 5K & Fun Run**

DTRF’s September Special Events:

- **September 7th, 4 PM EST:** DTRF Facebook *LIVE* Event #1 – **“Fundraising for Answers”** with Debbie Nathan, DTRF Development Director
- **September 14th, 4 PM EST:** DTRF Facebook *LIVE* Event #2 – **Patient Story Feature - TBD**
- **September 21st, 4 PM EST:** DTRF Facebook *LIVE* Event #3 – **DTRF Team Live from Philadelphia**
- **September 22nd-24th:** **DTRF Together We Will Weekend and RFA 5K & Fun run**

DTRF Social Accounts to Follow/Share/Tag:

- **Facebook:** [Facebook.com/desmoid](https://www.facebook.com/desmoid)
- **Twitter:** [@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/)

Partner Social Media Sample Language:

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

Twitter:

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

- *Suggested graphic: TBD*

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

- *Suggested graphic: TBD*

Other Social Media Platforms:

Post #1:

September is #DesmoidTumorAwarenessMonth!

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

#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, live virtual events, and more, please follow the Desmoid Tumor Research Foundation, engage and share!

- *Suggested graphic: TBD*

Post #2:

September is #DesmoidTumorAwarenessMonth!

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

Desmoid tumor patients are used to living with the "unknown" that comes with this #raredisease diagnosis. However, progress is underway. The FDA is currently reviewing @SpringWorks Therapeutics (tag) New Drug Application for the first-ever FDA-approved therapy for desmoid tumors. This exciting news along with additional promising clinical trials are providing much-needed hope to desmoid tumor patients worldwide.

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

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Graphics:

[CLICK HERE](#) to access the DTAM Partner Graphics folder, which includes:

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

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

Thank you for helping to raise #DesmoidAwareness!

- *Suggested graphic: TBD*

Existing Content to Share Throughout September:

Patient Stories in the Media:

- **Gabe (2023)**
<https://www.fox17online.com/sports/blitz/west-catholic-senior-gabe-augdahl-aims-to-bring-awareness-to-desmoid-tumors>
- **Stephanie (2023)**
<https://patientworthy.com/2023/04/20/rare-community-profiles-stephanies-desmoid-tumor-journey/>
- **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/>
- **Dana (2023)**
<https://www.mskcc.org/news/nirogacestat-new-desmoid-tumor-t>

[reatment-improves-outcomes-people-sarcoma?fbclid=IwAR1ASmhb271lgQUiTI-tJ1CSiCvj-VjghAiL3P7sOqRol-stKbRG02QJssk](https://www.facebook.com/DesmoidTumorAwareness/?fbclid=IwAR1ASmhb271lgQUiTI-tJ1CSiCvj-VjghAiL3P7sOqRol-stKbRG02QJssk)

Other Awareness Content

- **"How Dr. Alessandra Maleddu is Increasing Desmoid Tumor Awareness (Pts. 1 & 2)"** October 11-12, 2022, by Jessica Lynn
<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/>
- **"Nirogacestat May Offer an Additional Treatment Option for Desmoid Tumors"** Aug 4, 2023, Brian Van Tine, MD, PhD
<https://www.cancernetwork.com/view/nirogacestat-may-offer-an-additional-treatment-option-for-desmoid-tumors>
- **"Brave/Roar Mashup" by #DesmoidSurvivor DeAnn Sorenson & Family (2020)**
<https://vimeo.com/manage/videos/462777772>

Information and Resources

- **"What's in a Name? 'Cancer' & Desmoid Tumors" with Dr. Raphael Pollock (The Ohio State University) (Sept. 29th, 2021)**
<https://vimeo.com/manage/videos/620324631>
- **DTRF "Diagnosis and Treatment"**
<https://dtrf.org/diagnosis-and-treatment/>
- **DTRF "FAQs"** <https://dtrf.org/faqs/>
- **DTRF "Newly Diagnosed"** <https://dtrf.org/newlydiagnosed/>
- **Global Consensus Paper on desmoid tumor treatment**
<https://dtrf.org/consensus-paper/>
- **Clinical Trials for Desmoid Tumor Patients**
<https://dtrf.org/clinical-trials/>

- **Clinical Trials 101 – Dr. Breelyn Wilky (University of Colorado)** <https://vimeo.com/387733174>

THANK YOU!

