



**Desmoid  
Tumor  
Research  
Foundation**



**Research, Advocacy,  
Awareness, and  
Support**

**FUNDRAISING TOOLKIT**

## Highlights

Discoveries made through desmoid tumor research can potentially have an impact on common cancers such as breast, colon, ovarian, and others.

<p><b>1</b> NEW FDA-Approved Drug OGSI<sup>VEO</sup> (nirogacestat) ★ First drug with desmoid tumor indication</p> <p><b>1</b> Revised Global Consensus Paper ★ Partially funded treatment guidelines for desmoid tumor management</p> <p><b>3</b> 2024 DTRF-Funded Research Grants</p> <p><b>27</b> Medical Institutions and Industry Partners Represented at DTRF Research Workshop</p> <p><b>24</b> Recorded Scientific/Educational Videos Featured on DTRF.org Created for patients, clinicians and researchers</p> <p><b>31</b> International Medical Advisory Board Members Guiding DTRF's research priorities</p>	<p><b>1</b> NEW Desmoid Tumor Cell Line</p> <p><b>2</b> Desmoid Tumor Awareness Facebook Live Events Highlighting the desmoid tumor patient experience</p> <p><b>1</b> Desmoid Tumor Natural History Study ★ Published two posters at ESMO 2024 Sarcoma and Rare Cancers Congress</p> <p><b>145</b> Registrants at the DTRF Annual <i>Together We Will</i> Weekend</p> <p><b>12</b> Cases Presented at DTRF Int'l Virtual Tumor Boards</p> <p><b>2,077</b> Participants in Desmoid-Specific CME Accredited Programs Educating clinicians</p>
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As we **uncover answers**, we work tirelessly to provide patients and caregivers with the resources, information, and opportunities needed to be **informed advocates** in their care.

*I have never seen a group of people able to mobilize companies and the FDA like this!!*

JEAN PATY, PHD

VP, PATIENT CENTERED ENDPOINTS, IQVIA

**We are undaunted.**



# Fundraising Impact

## Our Mission: Cure Desmoid Tumors

The Desmoid Tumor Research Foundation (DTRF) empowers and unites everyone committed to finding answers for the desmoid tumor community. We aggressively fund desmoid tumor research, accelerate the development of improved therapies, drive collaborations among clinicians and researchers worldwide, and support patients and doctors through education.

**Our goal is to find a cure for each and every patient diagnosed with this rare disease.**

## The Urgency

With only 5-6 per million people diagnosed each year, desmoid tumors are exceedingly rare. Outside of large academic medical centers and sarcoma specialists, awareness of these invasive and destructive tumors is low. Funding to study rare diseases, like desmoid tumors, is scarce.

Organizations like the DTRF are critical to advancing the science to help our patients.

## Become a DTRF Changemaker

The DTRF can only continue our progress with fundraising support from our community and supporters. Our past do-it-yourself (DIY) fundraisers have told us the experience brings them joy, purpose, empowerment, and a strong sense of community. Fundraising for the DTRF not only helps us in our mission to find more answers for desmoid tumor patients, but it's also a great way to connect with others, team building, and have some fun at the same time.

Join this special community of “DTRF Changemakers,” who are essential to raising awareness for this rare disease.

[Join the Changemakers Facebook Group](#)



## Connect with the DTRF

With guidance from the DTRF's Development Director, Debbie Nathan, leading your own do-it-yourself fundraiser is now easier than ever.

- **Don't do it alone!** Debbie is here to help you get started and answer important DIY fundraising questions.
- **Learn more about the DTRF.** Take a moment to explore DTRF.org. Visit our *About DTRF* page to familiarize yourself with our story, mission, and impact to help you communicate with potential supporters.
- **Reach out if you need assistance.** The DTRF team is always here for you. Please reach out at any time if you need help during your fundraising experience.



**Questions?** Email Katie Doyle Myers at: [katie@dtrf.org](mailto:katie@dtrf.org)

## Perks of Fundraising with the DTRF

Take advantage of all the DTRF has to offer your fundraising event.

- **Click the button** below to launch your own personal fundraising page to track your donations, share your personal story and event information.
- **Download** the “Benefiting the DTRF” logo for your event promotional materials (page 9)
- **Social Media and Email Templates** to share with potential supporters (page 9)
- **DTRF awareness pens, bracelets, and banners** for your fundraising event!

Create Your DTRF Fundraising Page



### THINGS TO CONSIDER:

#### START EARLY

Start training/planning and fundraising together - post a photo on social media and link to your fundraising page to kickoff your journey!

#### ASK EVERYONE

People can't say “yes” if you don't ask. Never assume that someone isn't interested in supporting your fundraiser.

#### SEND A REMINDER

If you're nervous to send out a second email, don't be! Did you know the average person needs six reminders to get involved?

## ★ **HOST AN ENDURANCE RACE**

**WHAT IT IS:** You can choose any distance! From 5K to a marathon, you can join a cycling event, triathlon, or even consider a Tough Mudder! After you register for a race, you can ask for support from your friends and family on a variety of social media channels by sharing the link to your DTRF fundraising page. When you race while supporting the DTRF, you can hit a personal goal while raising awareness for desmoid tumor patients!

**WHAT YOU'LL NEED:** fundraising page, race entry, training program, sneakers

## ★ **COMMUNITY WALK**

**WHAT IT IS:** You can take the lead on planning your own 5K walk in your neighborhood. Invite fellow walkers or sign up for an event that is already happening! Want to host your own walk - the first step is choosing the venue and date – as simple as that!

## ★ **HOST A DINNER PARTY**

**WHAT IT IS:** Hosting a fundraising dinner party at home or at a restaurant is a great way to raise money and awareness for the DTRF. Gather your family and friends and turn your dining room into a restaurant.

**WHAT YOU'LL NEED:** venue, food, beverages, volunteers, audio/visual, entertainment, emcee, invitations, decorations, ticket sales, auctions, sponsorship

## ★ **AUCTION OR OPPORTUNITY DRAWING**

**WHAT IT IS:** An auction or an opportunity drawing can be a simple and fun way to raise money. Auctions can be held live or silent. Items can be donated by local businesses or could even be a fun talent or skill that one person could offer.

**WHAT YOU'LL NEED:** bid sheets, auction/drawing items, storage

## ★ SPORTING TOURNAMENT

**WHAT IT IS:** Grab your family and friends to fundraise by putting together a fun sporting event! Organize a tournament based around your favorite sport: whether it's baseball, golf, swimming or basketball, and have participants pay a fee to participate in the event. The participants can solicit support from friends to bring in additional revenue.

**WHAT YOU'LL NEED:** field, court or location to host your sporting event, sporting equipment, signage, players and teams



## ★ FITNESS CLASS

**WHAT IT IS:** Participants pay a fee to participate in an activity for a predetermined amount of time. To raise even more money, they can solicit pledges from family and friends for support. You can have a "Charity Ride" cycling class or another fitness class where people reserve their spot through their donation.

**WHAT YOU'LL NEED:** a place to host the class, gym support, marketing materials, signage, method to collect the class fee



## ★ SCHOOL/WORK-FOCUSED EVENTS

**WHAT IT IS:** A school or work group can participate in a wide array of events together. These events foster collaboration among students or coworkers and can be fun any time of year.

### EXAMPLES:

- *Dress Down Day* – have each colleague make a \$5 donation on one day of the week so they can wear jeans to the office.
- *Class or department competitions* – starting a friendly competition between different classes or departments can be a great way to generate revenue. It can be a chili cook-off or a fun athletic event.
- *Change drive* – have a class or department try to raise the most pennies. You can put quarters in your competitor's change jar, and this will raise more money while also canceling out 25 of their pennies!



## HAVE FUN WITH YOUR FUNDRAISER!



Pick something you like to do and turn it into a fundraiser. **We're here to help!**



### OTHER IDEAS:

- Art Show
- Garage/Yard Sale
- Bake Sale
- Car Wash
- Restaurant Benefit Night
- Talent Show

**New to fundraising? Have no fear!**

**Check out these fundraising ideas below:**

- 1 HOST A LOCAL SPORTS EVENT:** Contact your local high school or college to see if a portion of ticket sales for a certain event/game can go toward your fundraiser.
- 2 GIFT YOUR BIRTHDAY GIFTS:** Tell your family and friends that in lieu of a traditional gift for your birthday or anniversary, you would like them to make a donation to the Desmoid Tumor Research Foundation (DTRF) through RFA.
- 3 GIVE BACK NIGHTS:** Ask your favorite local restaurant, coffee or yogurt shop to donate part of their proceeds for a day!
- 4 PENNY WARS:** This is a fun way to challenge different studios, workout classes or other groups. Set up a jar where people can put pennies in for positive points and silver or cash for negative points.
- 5 CELEBRITY BARTENDER:** Do you know a local celebrity, news anchor, radio host or athlete? Ask them to bartend for a night and donate all the tips!
- 6 MATCHING GIFTS:** Many employers will match their employee's team donation. But, if not, ask your employer if they'll match what you personally raise. Or consider turning your personal gift into a match for your team!
- 7 VOLUNTEER GRANTS:** What better way to fundraise than volunteering for a cause you care about? Many employers will make donations on your behalf based on your volunteer hours. Find out if your employer offers this [here](#).
- 8 VIRTUAL BAKE SALE:** Have a famous recipe? Sell it to your friends and family and put the proceeds towards your fundraiser. Use your team to help promote it to their network and plan a fun pick-up place to get your team together. This works great around holidays!
- 9 VENMO:** It only takes ten \$10 donations to get to your \$100 goal! Set up a Venmo account as an easy way to collect small donations. Create a QR code right to the Venmo Account and put up flyers in your work lunch room.
- 10 HOST A CLASS:** Have a hobby you love? Host a yoga, cycling, or cooking class for donations towards your fundraiser!



**The most effective way to  
fundraise is to... ASK!**

Email outreach and social media (Facebook, Instagram, LinkedIn, etc.) are valuable tools for fundraising. Take advantage of the following tips and templates to help you along the way!

## ★ SOCIAL MEDIA TEMPLATES

Click the button below to view and/or download the DTRF social media posts to help you promote your DTRF fundraising page.

[Download Social Media Kit](#)



## ★ EMAIL TEMPLATES

To help you share your fundraiser, click the button below to download and customize DTRF email templates to spread the word about your fundraiser.

[Download Email Templates](#)

## SOCIAL MEDIA ADVICE

**POST OFTEN:** There are so many ads, news updates, and information that your posts probably aren't being seen by all your friends. Don't be afraid to make 2-3 posts a week with a link to your fundraising page.

**INCLUDE PICTURES:** Make the posts interesting by adding pictures of your event planning in progress, one of you on a training run if you're participating in a race, or a photo of the person you are fundraising for!

**THANK AND TAG:** People appreciate being recognized! Be sure to thank them and tag them in a post for their donation. Saying thank you shows others they can support you too!



**Questions?** Email Katie Doyle Myers at: [katie@dtrf.org](mailto:katie@dtrf.org)

★ Use this checklist as a guide to planning your event or create your own.

Event Name: \_\_\_\_\_

Date: \_\_\_\_\_

Location: \_\_\_\_\_

Planner(s): \_\_\_\_\_

## 6 MONTHS - 1 YEAR AHEAD

- Determine event goal, name, and location
- Determine event budget
- Identify vendors needed for your event ex. Food, Décor, Audio/Visual, Entertainment, Speaker
- Select a volunteer committee to help in planning the event
- Begin promotional materials
- Develop sponsorship levels

## 1 MONTH BEFORE EVENT

- Order any items necessary
- Finalize all logistics and event schedule
- Train volunteers on their event responsibilities
- Complete guest list
- Send reminders to attendees

## DAY OF EVENT

- Set up venue/event
- Verify all vendors are in place Thank sponsors and attendees at the event
- Enjoy your hard work and have fun!

## POST-EVENT

- Thank everyone for participating
- Share final amount of money raised to supporters
- Ask for feedback & suggestions for next event

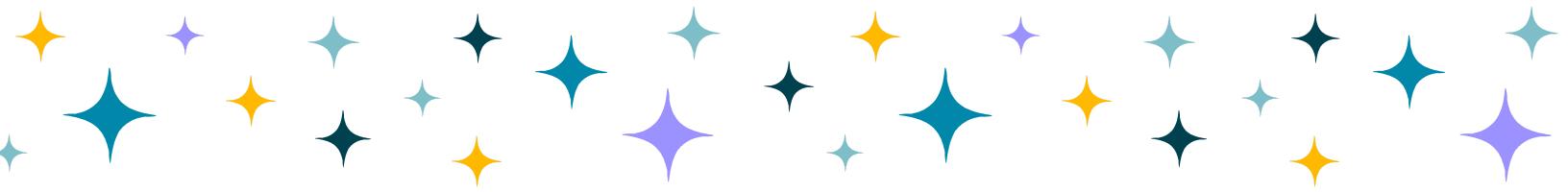
**Please note:** This checklist may not apply to your event or your event may have details and logistics not listed.

## 2 MONTHS AHEAD

- Create event schedule
- Finalize vendors
- Venue logistics (ex. Parking, Registration, Signage)
- Continue promoting event
- Design and order t-shirts
- Recruit volunteers for day of event

**Have fun with fundraising and get creative.** To raise \$250, you can simply ask 25 of your family or friends for \$10 each or try any of these tried and true ways to hit your personal fundraising goal.

- 1. Email your friends and family.** Copy and paste the link to your RFA fundraising page into an email or text the URL to your friends and family!
- 2. The Mighty Pen.** Try mailing a letter to friends, family, co-workers, and neighbors asking for their support. Let them know why you are raising money. If you have a personal connection, share your story. Don't forget to send a thank you note to people who donate!
- 3. One-A-Day.** Ask a different person to make a contribution each day. If you get five \$50 gifts, you will have raised \$250 in less than a week! Did you know the main reason people don't donate is that they were never asked?
- 4. Post It.** Use social media like Instagram, Facebook, Twitter, LinkedIn, or other channels to link to your RFA fundraising page and raise awareness about desmoid tumors.
- 5. Think about the friends you have supported with donations.** It's their turn to support you. Reach out to them!
- 6. Talk it up.** Ask for a few minutes on the agenda of any Zoom or Skype meetings you attend. Explain why you are participating in RFA fundraising and ask for everyone's support. Even small contributions will push you toward your fundraising goal.
- 7. Celebrate.** Tell your friends and family that instead of a traditional birthday or anniversary gift, you would like them to make a donation to RFA. You'll feel good... and they will, too!
- 8. Virtual Party Time.** Get creative and throw a virtual party for friends and family! Using Skype or Zoom, you can host a virtual bingo night, happy hour, or game night. Netflix Party will let you watch a movie "together" with friends and family while using a real-time chat feature. Ask for a \$5 donation from attendees and enjoy a fun night together!
- 9. Online Teaching.** Are you skilled a cooking? Creative with a paintbrush? Great at yoga? Ask for \$10 donations from participants and host a virtual class for them to follow along at home.
- 10. Don't Miss an Opportunity.** Change the recording on your voicemail to mention RFA and how callers can make a donation. Then, when they call back, ask them to support you with a contribution. Ask for support in your signature line on emails you send out. Be sure to include your fundraising page link so it will be easy for them to donate.



# 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!

