

2024  
**REA**  
WALK



**JOIN US IN-PERSON:**

Sunday, September 22 ✦ Houston Zoo

**Join us In-Person in Houston and Virtually  
Anywhere in the World!**

**FUNDRAISING TOOLKIT**

## 2023 Impact Report by the Numbers

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

**1** **NEW FDA-Approved Drug** ✨  
**OGSIVEO (nirogacestat)**  
First drug with desmoid tumor indication

**1** **NEW Desmoid Tumor Cell Line**

**136** **Direct Requests for Support  
from Patients & Caregivers**

**3** **Mental Health Webinars**  
Created to support patients

**6** **2023 DTRF-Funded  
Research Grants**

**2** **Actively Recruiting Clinical Trials**

**30** **Medical Institutions and  
Industry Partners**  
Represented at DTRF Research Workshop

**1** **Desmoid Tumor Natural History Study** ✨  
Poster won category award at  
2023 Connective Tissue Oncology Society Conf.

**8** **Recorded Scientific/Educational  
Presentations**  
Created to support patients

**163** **Registrants at the DTRF Annual  
*Together We Will* Weekend**

**4** **CME-Accredited  
Programs Launched**

**1** **NEW Set of ICD-10 Codes** ✨  
Specific to desmoid tumors

**32** **International Medical  
Advisory Board Members**  
Guiding DTRF's research priorities

**12** **Cases Presented at  
DTRF Int'l Virtual Tumor Boards**

The annual *DTRF Together We Will Weekend* facilitates scientific collaboration, fosters patient education and connection, and hosts our largest signature fundraiser, *Running for Answers (RFA)*.

*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.**



Share this report [here](#). Copy & paste the link to help encourage others to support RFA!

## 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.**

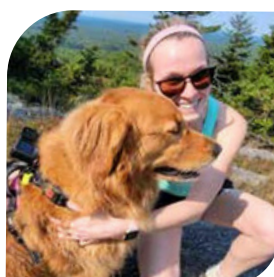
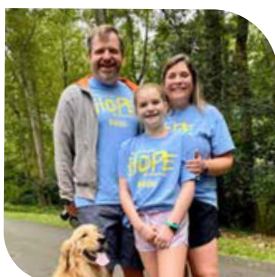
Outside of large academic medical centers and sarcoma specialists, awareness of these invasive and destructive tumors is low. Funding to study rare diseases, like desmoid tumors, is scarce. Organizations like the DTRF are critical to advancing the science to help our patients.

## About Running for Answers (RFA)

What's now the RFA Walk began in 2009 as Running for Answers (RFA), when desmoid tumor patient, Sera Snyder ran a half marathon to raise money for the DTRF. She wanted to make a bigger impact, and with a committed and caring group of friends, family and fellow patients, founded the Running for Answers 5 miler in 2010. Marrying her passion for running with her marketing talents, Sera and her small committee attracted over 350 runners and raised over \$65,000 for DTRF in what became the first annual Running for Answers event, now known as RFA.

## The RFA Impact

Today, RFA is the DTRF's signature annual fundraising event, raising more than \$1 million for the Foundation over its first 10 years. Funds raised are used to support our mission to find a cure for each and every desmoid tumor patient.



Are you a RFA participant or Team Captain? You are now part of the DTRF's signature fundraiser. Your participation directly supports our work toward a cure for each and every desmoid tumor patient. **We are grateful to have you and welcome you to the Running for Answers community!**

## Before the Event

**The months and weeks leading up to our event is the time to raise awareness, fundraise and recruit your team.** Participants who raise \$250 or more will earn fundraising incentives. Recruit a team by inviting friends, family, coworkers and neighbors to join the cause and fundraise with you. Top fundraising teams will be recognized at the walk.

## Day of the Event

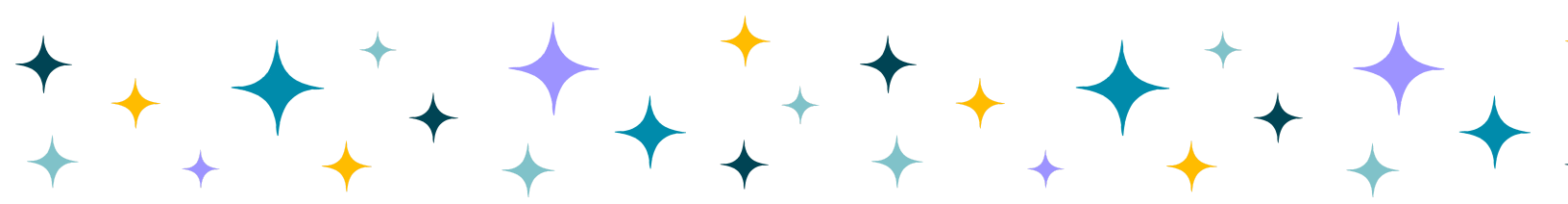
**Get ready for a FUN day, and don't forget to wear your craziest socks or dress as your favorite zoo animal!** With the weather almost always on our side, the RFA Walk promises to be a great event, filled with connection, comradery, and excitement. The event culminates with our Closing Ceremonies where our top teams are recognized. We plan to live-stream the Closing Ceremonies to include and recognize our virtual participants and teams.

## After the Event

The need for funding for desmoid tumor research doesn't end with RFA. **We hope you will continue to think of the DTRF when you plan your year-end giving.** Additional donations can be made via your fundraising page through the end of September, or donate on our website, [DTRF.org](https://DTRF.org).



**Keep the momentum going all year long!**



## Individual Participants

Use the link on the [DTRF.org](https://DTRF.org) homepage to get started. Then click the yellow **Register** button on the next screen. Our online registration and fundraising platform makes it easy. You can choose to register for the in-person event or simply fundraise virtually.

*You might choose to kick-start your fundraising with a donation made during registration.* At the end, you'll receive a confirmation email to claim your fundraising page.

## Team Captains

**Forming a team is a great way to amplify your fundraising efforts.**

Use the link on the [DTRF.org](https://DTRF.org) homepage to get started. Then click the yellow **Register** button on the next screen, and choose the option to **Create a Team**. Give your team a **Name** and a **Goal** (don't worry, you can edit this later). You can choose to register for the in-person event or do your fundraising virtually.

You might choose to kick-start your fundraising and set an example for your team with a donation made during registration. At the end, you'll receive a confirmation email to claim your team fundraising page. From here, we recommend inviting others to join your team! Our online registration and fundraising platform makes it easy.



## Team Members

To join a team, use the link on the [DTRF.org](https://DTRF.org) homepage to get started. Then click the yellow **Register** button on the next screen, choose the option to **Join a Team**, and select a team to join. You can register for the in-person event or do your fundraising virtually and still be a part of a team. *You might choose to kick-start your fundraising with a donation made during registration.*

**Our online registration and fundraising platform makes it easy to make a big impact on your team's goal.**

- 1 MAKE A PERSONAL DONATION** to lead by example!
- 2 SET A FUNDRAISING GOAL** for both yourself and your team.
- 3 PERSONALIZE YOUR FUNDRAISING PAGE** with your story and photo or video. Did you know those who customize their page raise 3X more on average?
- 4 RECRUIT TEAM MEMBERS** The more people you recruit, the more people to fundraise! Your team goal is a collective total. Share you team page link with friends, family, neighbors and coworkers. You'd be surprised who might step up to fundraise with you.
- 5 START FUNDRAISING TODAY** and get creative! The earlier you start, the more you'll raise. Send a link to your RFA fundraising page via text message or email, or post the link on your own social media accounts.
- 6 RAISE AWARENESS ONLINE** by using these **social media tools** on Facebook, Instagram, LinkedIn and more!
- 7 HOST A TEAM KICKOFF** such as a BBQ or picnic to get your team excited and use it as a fundraising opportunity!
- 8 CREATE TEAM SHIRTS** to show your team spirit! Consider selling your shirts to raise money for your team.
- 9 SHARE PROGRESS** and updates towards your goal. People want to help! Let them know how far away you are from your goal.
- 10 CELEBRATE!** Celebrate your wins and any participants on your team who hit their fundraising goal. Find a fun way to celebrate when you hit your team goal!

**...and don't forget to HAVE FUN!**



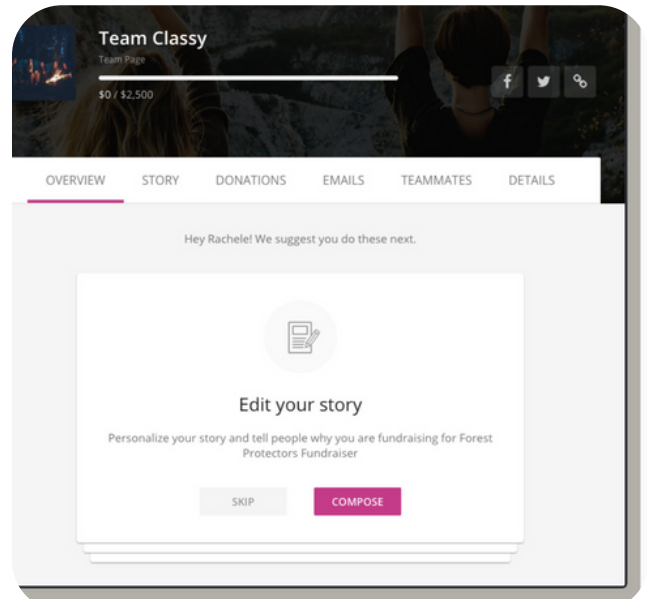
# Customizing Your Fundraising Page



## Team Captains

Visit your team fundraising page (use the link in your confirmation email) and select the **Manage** button. It will be at the top-right of the screen on a desktop and at the bottom-right of the banner image on mobile devices.

The first thing you see when you open the editor is the **Overview** tab. From here, you can view some cards with suggested next steps and access other content tabs. There are two content tabs that control the appearance and details of your fundraising page: *the Story tab and the Details tab.*



If this is your first time viewing the editor, we recommend completing the cards on the **Overview** tab. They will help you edit your story, make the first donation to your team, and start recruiting your team members. Links that provide more detailed instructions for each tab can be accessed on our website. Visit [DTRF.org/rfa](https://DTRF.org/rfa).

## Team Members & Individual Participants

Take a look at the general instructions above for Team Captains. Customizing an individual page is very similar. You just won't see the **“Teammates”** tab. If this is your first time viewing the editor, we recommend completing the cards on the **Overview** tab. They will help you to add your photo, edit your story, make the first donation to your page, and ask for donations from friends and family. Links that provide more detailed instructions for each tab can be accessed on our website. Visit [DTRF.org/rfa](https://DTRF.org/rfa).

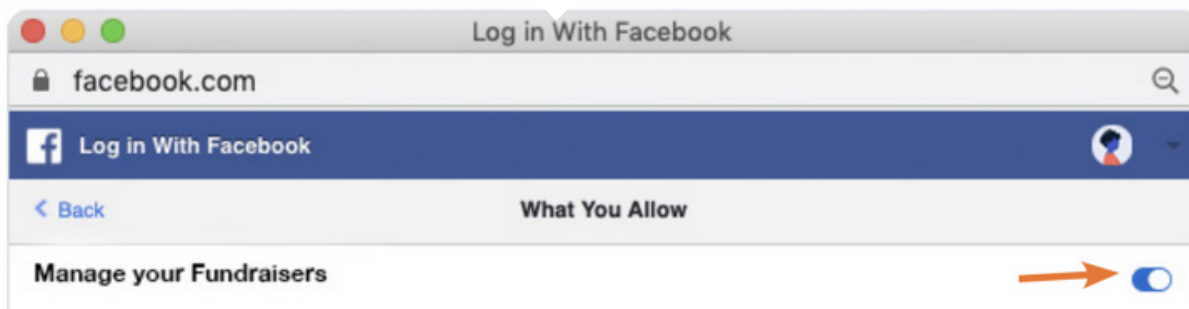
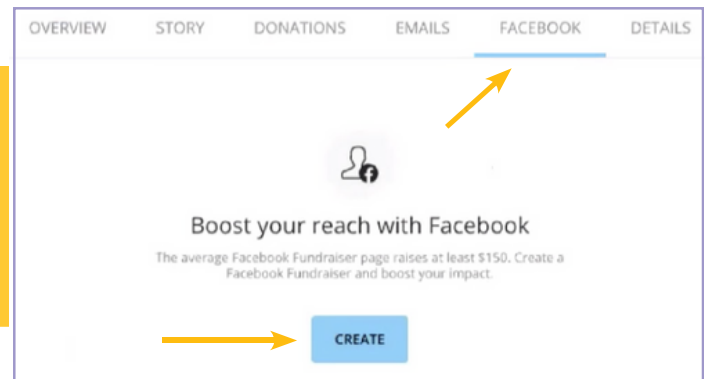


**SHARE. CONNECT. REACH YOUR GOAL!**

Connecting your RFA Fundraising Page to Facebook is an easy way to meet your supporters where they are. Your Facebook friends and family can easily donate to your fundraiser without leaving Facebook. Here's how to set it up!

## Set up your fundraising page to connect to Facebook:

1. Access your RFA fundraising page and login.
2. Choose **Manage** from the top right of your page.
3. Look for the Facebook tab and click **Create**.
4. After logging into Facebook, be sure the Manage your Fundraisers toggle is on!



After completing these steps, your Facebook fundraising page will be created automatically and appear on your Facebook activity feed. Select **View** on the tile that appears to visit your Facebook fundraising page.

Now you can share both fundraising pages to maximize your reach!

### TIPS:

- Your campaign details will automatically transfer over, and you can update them on your RFA fundraising page anytime.
- Google Chrome is the preferred browser for fundraising pages. If you are using a different browser, you may see an endless processing screen.
- To fix this, go to your address bar and look for a blocked pop-up notification. Select it and allow the pop-up to display to create your fundraising page.



# RA Incentives



We've assembled some great incentives to thank you for fundraising for the DTRF and supporting our mission to find a cure for each and every desmoid tumor patient. Starting at \$250, you can earn exclusive DTRF items to help raise awareness and showcase your support!



**\$250+**

Desmoid Tumor Awareness T-Shirt  
EXCLUSIVE!



**\$500+**

DTRF Tote Bag  
Plus T-shirt!



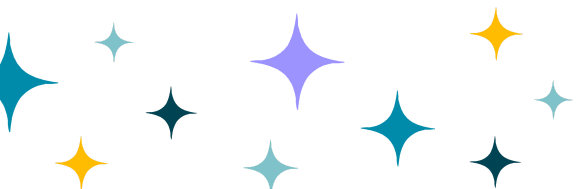
**\$1000+**

Insulated Travel Mug  
Plus T-shirt and  
Tote Bag!



**\$2000+**

DTRF Earbuds  
Plus T-shirt,  
Insulated Mug and  
Tote Bag!



***NOTE:** All fundraising donations, including matching gifts, must be received on or before September 25, 2024, to qualify for incentives. Alternative incentives may be offered due to limitations in product availability.*



# 10 EASY WAYS TO RAISE \$250 OR MORE!

**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 donated to.** 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 at 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.



# 10 Ways to Fundraise



## 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 Desmond 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... ASK!**

# 2024 RA WALK



## Thank you!

On behalf of the entire DTRF team and the patients everywhere who rely on us to advance desmoid tumor science for the promise of a better tomorrow, we thank you. With deep gratitude, we hope to see you in Houston!

