



September 23 is #RareCancerDay

Rare Cancer Day 2026 Toolkit

As a voice in the rare cancer community, as well as the broader rare disease and cancer communities, you are a great fit to drive the conversation leading up to Rare Cancer Day on **September 23!** The National Organization for Rare Disorders (NORD®) has created the following toolkit to help you generate excitement all month in the lead-up to the 23rd. Encourage your colleagues and networks to join you in spreading the word using this guide!

Included are helpful tips for engaging on social media and with reporters or interviewers, as well as shareable infographics and other rare cancer-related resources from NORD. We encourage you to customize and personalize the content so that it is most authentic to you and your followers. Thank you for spreading the word about Rare Cancer Day and the 1 in 4 cancer patients diagnosed with rare cancers!

Social Media Tips

- **Attach an image to your post** – Use one of the assets we have provided below or get creative!
- **Use the hashtag #RareCancerDay** – Be a part of the conversation this year by including the official hashtag in all your posts. That helps others in our Coalition share your content!
- **Engage with your followers** – If you receive questions or comments about your posts, we encourage you to respond to them and start conversations!
- **Tag or message your network** – Are there people or organizations you would like to see get involved with Rare Cancer Day? Tag them in your posts to let them know that you want their help in spreading the word or send them this toolkit in a DM or email.

Social Media Properties

The official awareness day hashtag is **#RareCancerDay**. Please use this hashtag in all your posts before and on the day to create one centralized conversation.

Feel free to tag NORD in your posts using the profiles below:

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord_rare

BlueSky: @nordrare.bsky.social

Image Assets for Social Media Posts

These infographics were created to help you promote Rare Cancer Day, so please download them for use on your social media platforms. They can also be included in emails and on your website!

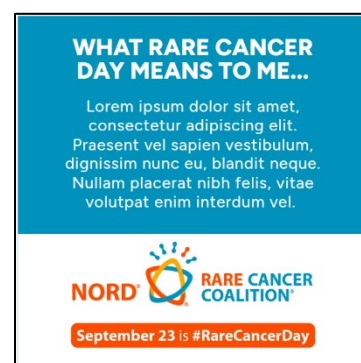
DOWNLOAD EDUCATIONAL SOCIAL GRAPHICS



Customizable Social Media Posts

Below, you'll find customizable social media copy that you can tailor for easy sharing in the lead-up to Rare Cancer Day on September 23. Pair your post with one of the infographics we've provided or get creative with content you feel will resonate best with your network.

You can also personalize our [“What Rare Cancer Day Means to Me” Canva template](#) by adding your own message, then download and share it with your network.



General

“NORD’s Rare Cancer Coalition is dedicated to give hope to patients and caregivers by eliminating the challenges faced by people affected by rare cancer.”

Twitter

- September 23 is #RareCancerDay! Join the zebra herd and help @RareDiseases raise awareness and spread the word for #RareCancer. Visit <https://bit.ly/3EHaY7o> to learn more. {upload image provided or your own}
- Nearly 1 in 4 cancer diagnoses are rare. You may be rare, but you’re not alone! Learn how you can get involved to raise awareness on September 23 for #RareCancerDay: <https://bit.ly/3EHaY7o> {upload image provided or your own}
- Have you or a loved one been affected by #RareCancer? #RareCancerDay is coming up on September 23. Join NORD (@RareDiseases) and the Rare Cancer Coalition in raising awareness for #RareCancer this year. <https://bit.ly/3EHaY7o> {upload image provided or your own}

Facebook/LinkedIn

- September 23 is #RareCancerDay! @NationalOrganizationforRareDisorders and the Rare Cancer Coalition invite you to join the zebra herd in spreading the word about rare cancer and this important awareness day. Visit <https://bit.ly/3EHaY7o> to learn more about how you can get involved. {upload image provided or your own}

- Did you know that nearly 1 in 4 cancer diagnoses are rare? You may be rare, but you are not alone! Learn more about rare cancer and how you can help @NationalOrganizationforRareDisorders and the Rare Cancer Coalition raise awareness for #RareCancerDay on September 23. <https://bit.ly/3EHaY7o> {upload image provided or your own}
- Have you or a loved one been affected by a rare cancer diagnosis? #RareCancerDay is coming up on September 23. Join @NationalOrganizationforRareDisorders and the Rare Cancer Coalition in raising awareness for individuals with rare cancer. Learn how you can get involved on this important, upcoming day here: <https://bit.ly/3EHaY7o> {upload image provided or your own}

Instagram

- Did you know that nearly 1 in 4 cancer diagnoses are rare? You may be rare, but you are not alone! Learn more about #RareCancer and how you can help @nord_rare and the Rare Cancer Coalition raise awareness for #RareCancerDay on September 23. <https://bit.ly/3EHaY7o> {upload image provided or your own}
- Have you or a loved one been affected by a rare cancer diagnosis? #RareCancerDay is coming up on September 23. Join @nord_rare and the Rare Cancer Coalition in raising awareness for individuals with rare cancer. Learn how you can get involved on this important, upcoming day here: <https://bit.ly/3EHaY7o> {upload image provided or your own}

Rare Cancer IAMRARE® Registries

This is an important opportunity for many in our Rare Cancer Coalition® who operate patient registries to potentially reach more patients and grow their IAMRARE databases. Please consider sharing some or all of the following on your social media and email channels:

- A Cure in Sight: <https://acureinsight.org/om-registry/?v=7516fd43adaa>
- Chondrosarcoma Foundation: <https://chondrosarcoma.iamrare.org/>
- The EHE Foundation: <https://fightehe.org/registry/>
- Desmoid Tumor Research Foundation: <https://dtrf.org/patient-registry/>
- Gorlin Syndrome Alliance: <https://gorlinsyndrome.iamrare.org/>
- Raymon A. Wood Foundation: <https://hptumorregistry.iamrare.org/>
- TBRs Community: <https://tbrsregistry.iamrare.org/>
- VHL Alliance: <https://databank.vhl.org/>