

2019 Rare Cancer Day Social Media Toolkit



October 1 is #RareCancerDay
Show Your Support by Spreading the Word

As a voice in the rare cancer community, you can be a huge support to drive the conversation leading up to Rare Cancer Day 2019! The following is a social media toolkit that will help you to share content and generate excitement before the big day (October 1), NORD has officially announced this new awareness day via a [press release](#) (Aug 29) – now it's time to encourage your colleagues and networks to follow the conversation online will help spread the word!

The toolkit includes helpful tips for using social media, customizable template posts, links to official social media properties including profile handles, hashtags and digital assets. Upon receipt of the toolkit, we ask you to review the material and personalize the content so that it is most authentic to you and your followers. You can then begin sharing!

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[Helpful Tips for Social Media](#)

- **Attach an image to your post** – feel free to use [these images](#), this [infographic](#), or get creative!
- **Engage with your followers** – if you receive questions or comments about your posts, respond to them! Social media is all about the engagement between followers and having a conversation.

- **Tag your followers** – is there someone that you know would like to get involved with Rare Cancer Day? Tag them in your posts to let them know that you want their help in spreading the word.
- **280 characters** – is the character limit on Twitter.
- **2,200 characters** – is the character limit on Instagram.
- **Short and sweet** – Facebook and LinkedIn do not have character limits, but shorter posts tend to be more effective.

Social Media Properties

The official awareness day hashtag is **#RareCancerDay**. Please use this hashtag in all of your posts before and during the day in an effort to create one centralized conversation about the important topics we will be discussing.

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

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord_rare

The **image** was created to promote the event, please feel free to download and share it on your social media platforms.

Customizable Post Templates

Below you will find customizable post templates that you can fill in for easy sharing on social media, beginning on August 29 and leading up to Rare Cancer Day on October 1. Share a Rare Cancer Day **infographic** or feel free to get creative and share content that you feel would resonate best with your network.

Twitter

- Did you know about 1 in 5 people living with cancer in the U.S. have a rare cancer? October 1 is #RareCancerDay! @RareDiseases & the #rarecancercoalition invite you to join the zebra herd and spread the word about rare cancers! Visit bit.ly/2ZmL3yY to learn more. {upload image provided or your own}
- “I’ve never heard of that!” How many times have people living with rare cancers gotten that response? You may be rare, but you’re not alone! Join the zebra herd and spread the word for #RareCancerDay on Oct. 1. {upload image provided or your own}
- Have you or a loved one been impacted by a rare cancer? Join the rare cancer zebra herd and BE heard! Oct 1 is #RareCancerDay - share this **infographic** and help spread the word. Visit bit.ly/2ZmL3yY for more information. {upload image provided or your own}.

- Rare cancer research can potentially advance the science for cures for more common cancers, yet research remains vastly underfunded. Let's change that! Oct. 1 is #RareCancerDay. Visit bit.ly/2ZmL3yY for more information. {upload image provided or your own}.
- Genetic testing is critical for diagnosing rare diseases, but rare cancers are different! Molecular profiling testing can identify possible treatments in rare cancers, but often isn't offered or covered by insurance. Spread the word for #RareCancerDay, Oct. 1. {upload image provided or your own}

Facebook/LinkedIn/Instagram

- Did you know approximately 1 in 5 people living with cancer in the United States are diagnosed with a rare cancer¹? Or that all pediatric cancers are rare? October 1, 2019 is #RareCancerDay! {tag NORD on channel of your choice} and the Rare Cancer Coalition invite you to spread the word about rare cancers! Visit bit.ly/2ZmL3yY to learn more. {upload image provided or your own}
- “I've never heard of that!” How many times have people living with rare cancers gotten that response when sharing their diagnosis? Living with an uncommon cancer may leave you feeling isolated. Remember: you may be rare, but you're not alone! Get on board with {tag NORD on channel of your choice} and the Rare Cancer Coalition - join the herd and spread the word for #RareCancerDay on October 1! {upload image provided or your own}
- There is often significant delay for rare cancer patients to get an accurate diagnosis, typically longer than patients with more common cancers. Timely diagnosis can save lives². Join the zebra herd and spread the word about rare cancers! #RareCancerDay is October 1. Visit bit.ly/2ZmL3yY for more information. {upload image provided or your own}.
- Rare cancer research can potentially advance the science for cures for more widespread cancers, yet research remains vastly underfunded. It is time for that to change! Oct. 1 is #RareCancerDay. Visit bit.ly/2ZmL3yY for more information. {upload image provided or your own}.
- Genetic testing is critical for diagnosing rare diseases, but rare cancers are different! Molecular profiling testing can identify possible treatments in rare cancers, but often isn't offered or covered by insurance. Spread the word for #RareCancerDay, Oct. 1. {upload image provided or your own}

¹ The Burden of Rare Cancers in the United States
 Carol E. DeSantis, MPH 1*; Joan L. Kramer, MD2; Ahmedin Jemal, DVM, PhD3, May 2017
<https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21400>

² Evans RE, Morris M, Sekhon M, et al. Increasing awareness of gynaecological cancer symptoms: a GP perspective. *Br J Gen Pract.* 2014; 64: e372- e380.
[Crossref PubMed Web of Science® Google Scholar](#)

Images

Images provided below are for your information. **Please use the links below to download high-resolution graphics.**

Images: https://rarediseases.org/wp-content/uploads/2019/08/NORD_RareCancerAwareness_Logos.zip

Infographic: https://rarediseases.org/wp-content/uploads/2019/08/NORD_RareCancer_Facts.zip



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Approximately **1 in 5** people living with cancer in the United States are diagnosed with a rare cancer.

All pediatric cancers are rare.¹



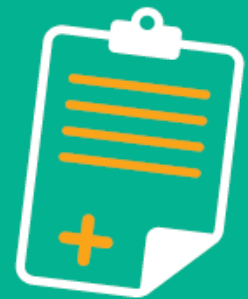
1. The Burden of Rare Cancers in the United States Carol E. DeSantis, MPH 1*; Joan L. Kramer, MD2; Ahmedin Jemal, DVM, PhD3, May 2017
<https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21400>



The 5-year survival rate is **lower for patients with a rare cancer** than for those diagnosed with a more common cancer.¹

1. The Burden of Rare Cancers in the United States Carol E. DeSantis, MPH 1*; Joan L. Kramer, MD2; Ahmedin Jemal, DVM, PhD3, May 2017
<https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21400>

Efforts to **increase awareness of rare cancer** symptoms in patients and clinicians could lead to earlier detection and improvements in survival.²



2. Evans RE, Morris M, Sekhon M, et al. Increasing awareness of gynaecological cancer symptoms: a GP perspective. Br J Gen Pract. 2014; 64: e372- e380.
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