



NORD'S RARE DISEASE DAY TOOLKIT

For Rare Disease Day, NORD is encouraging our strongest supporters to show what makes them unique by joining our campaign, "Show Your Stripes." Over 25 million people in the US are affected by a rare disease and their stories and journeys are as unique as their stripes. This day is about celebration and awareness, and we want everyone to be a part of it.

A great way to show your stripes is by joining the conversation on social media. This toolkit will help you build your Rare Disease Day posts and provide a helpful guide on how to connect with NORD. Thank you for joining us in celebrating Rare Disease Day. Get ready to #ShowYourStripes!

GET STARTED

Here are some of NORD's social media profiles and hashtags. You can mention us in your posts or refer your followers to our social channels for more information on Rare Disease Day:

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord_rare

Hashtags: #ShowYourStripes, #RareDiseaseDay, #LightUpForRare

SOCIAL MEDIA GRAPHICS

NORD has created social media images you may use to raise awareness and start conversations online. Please feel free to download the [zipped folder](#) and share the assets across your social media accounts.

Looking for a way to frame your profile on Facebook? Check out the official Rare Disease Day Facebook Frame [here](#).

HELPFUL HINTS

- 1) Add an image to your post. You can use one of the assets that we've created OR get creative! The "Show Your Stripes" theme is limitless, so have fun with it. You can share a video of yourself or your family to really connect with your viewers as well.
- 2) Tagging followers, public figures, leaders, celebrities, and more will encourage additional participation and engagement. If you know someone who may be interested in Rare Disease Day, tag them, and spread the word.
- 3) If you can, include a call to action in your post. The best way to raise awareness is to spread the word and encourage others to join in. Make sure you use clear wording, so your followers know what you're asking them and how they can join in on the celebration.
- 4) Social media should be social! Try to engage with your followers as much as you can. If you're getting questions and comments under your posts, respond and interact with them.
- 5) A character limit is the maximum amount you can write in your post. Spaces, letters of the alphabet, numbers, and punctuation all count toward a character limit. Here is a quick character limit guide, though posts that are shorter tend to perform better:
 - Twitter: 280 characters
 - Instagram: 2,200 characters
 - LinkedIn: 3,000 characters
 - Facebook: 5,000 characters

SAMPLE POSTS

Twitter:

Leading up to Rare Disease Day:

1. Mark your calendars, it's almost #RareDiseaseDay! On February 28, **[I/my family/my organization]** will be joining the #ShowYourStripes movement in support of the rare community. Learn more on @RareDiseases website: <https://bit.ly/US-RDD22>
2. #RareDiseaseDay is right around the corner and, **[I/my family/my organization]** will be wearing stripes in honor of the rare community. For more information on how you can #ShowYourStripes, visit @RareDiseases website: <https://bit.ly/US-RDD22>
3. It's almost time to #LightUpForRare! **[I/my family/my organization]** will be wearing #RareDiseaseDay colors to show support for those impacted by rare disease. Learn how you can get involved: <https://bit.ly/US-RDD22> @RareDiseases

On Rare Disease Day:

1. Today is #RareDiseaseDay and I, **[Insert name]**, am a proud **[member/supporter]** of the #RareDisease community. #ShowYourStripes and support the rare community today: <https://bit.ly/US-RDD22> **[Share a photo of yourself.]**
2. Are you wearing stripes today for #RareDiseaseDay? Join **[me/my family/my organization]** and @RareDiseases and spread the word about #ShowYourStripes . You can raise support for the rare community by getting involved now: <https://bit.ly/US-RDD22> **[Share a photo of you or your family/ organization wearing stripes]**
3. Today, **[share what you or your family/organization is doing for Rare Disease Day]** for #RareDiseaseDay! Share what you're doing in the comments! #ShowYourStripes **[Share a photo of you or your family/ organization]**
4. #RareDiseaseDay raises awareness for the 7,000+ #RareDiseases that affect over 25 million Americans! **[I/my family/organization]** will be joining @RareDiseases in celebrating the rare community. Learn how to #ShowYourStripes: <https://bit.ly/US-RDD22>
5. Since 2008, #RareDiseaseDay has created a global #RareDisease community that comes together to raise awareness for those affected by rare diseases. Join **[me/my family/ organization]** and @RareDiseases to celebrate the rare community. Get involved: <https://bit.ly/US-RDD22>
6. Today, we are illuminating **[our home/building/office]** in #RareDiseaseDay colors in honor of the rare community. Join **[me/my family/organization]** and #LightUpForRare! Learn how to get involved: <https://bit.ly/US-RDD22>
[Share a photo of you or your family/ organization wearing pink, green, blue and purple]

Facebook/Instagram:

Leading up to Rare Disease Day:

1. On #RareDiseaseDay I will be raising awareness for the rare community. Check out **[tag NORD on the channel of your choice]** on February 28 to join the celebration. Learn how you can #ShowYourStripes: <https://bit.ly/US-RDD22>
2. #RareDiseaseDay is just around the corner! **[I/my family/organization]** will be wearing stripes to honor the rare community. Join us and #ShowYourStripes: <https://bit.ly/US-RDD22>

On Rare Disease Day:

1. A disease is considered rare when it affects less than 200,000 individuals in the United States. **[I/my family/organization]** will be celebrating and raising awareness for those affected by rare diseases. Learn how you can get involved: <https://bit.ly/US-RDD22> #ShowYourStripes #RareDiseaseDay
2. #RareDiseaseDay falls on the rarest day on the calendar, Monday, February 28, to represent the more than 25 million Americans impacted by rare diseases! #ShowYourStripes in support of the rare community. Learn how you can join the movement: <https://bit.ly/US-RDD22>
3. My stripes are unique! I have **[Insert rare disease you're affected by]** and I am showing my stripes for #RareDiseaseDay. Learn how you can #ShowYourStripes: <https://bit.ly/US-RDD22>
4. **[Share your rare disease story - use the points below]** If you want to share your story visit **[tag NORD on the channel of your choice]** website: <https://bit.ly/US-RDD22> #RareDiseaseDay #ShowYourStripes
[Share a photo of yourself/your family]
 - a. Your name and the state you live in.
 - b. The rare disease you are affected by.
 - c. What does Rare Disease Day mean to you/your family?
5. Did you know that over 25 million Americans are affected by a rare disease? Today, we join **[tag NORD on the channel of your choice]** to celebrate and raise awareness for those affected by rare diseases. Learn more about #RareDiseaseDay and how to get involved: <https://bit.ly/US-RDD22>
6. Since 2008, #RareDiseaseDay has created a global rare disease community unified for one goal: uplifting and empowering those affected by rare diseases. **[I am/my family/organization is]** excited to join **[tag NORD on the channel of your choice]** as they bring light to many issues involving equity in social spaces and access to life changing treatments and studies for the rare community! Learn how you can #ShowYourStripes: <https://bit.ly/US-RDD22>
7. Let's #LightUpForRare! We want the world to be illuminated with #RareDiseaseDay colors in honor of the rare community. Learn how you can get involved: <https://bit.ly/US-RDD22>

SOCIAL MEDIA SUGGESTIONS

- Use the “Live” feature on your social media platforms! Go live for a few minutes to share your rare disease story or how you/your family will be spending Rare Disease Day. The live feature is offered on Facebook and Instagram.
- Spread the word about Rare Disease Day! Share or repost information about in-person or virtual events to increase attendance.
- Engage with NORD! NORD, along with our member organizations, will be posting frequently on our social media channels leading up to Rare Disease Day. We would love to see you commenting under posts, sharing the post with friends and family, or tagging your favorite celebrity or elected official under our posts. Your incredible efforts do not go unnoticed, and we rely on you to help bring awareness to the rare disease community.