



Rare Disease Day 2023 Social Media Toolkit

For Rare Disease Day, NORD is encouraging supporters to show what makes them unique by joining our campaign, “Show Your Stripes.” Over 25 million people in the United States 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!

Social Media Properties

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

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

rarediseaseday.us

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Social Media Graphics

NORD has created social media images you may use to raise awareness and start conversations online.

[CLICK HERE TO DOWNLOAD GRAPHICS FOR RARE DISEASE DAY 2023](#)

Helpful Tips for Social Media

- 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. Feel free to share a video as well!
- 2) **Tag your followers.** 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) **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. If there is a question that you can't answer, feel free to tag us in the comments and we'll help.
- 4) **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.
- 5) **Go live!** Use the "Live" feature on your social media platforms to 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.
- 6) **Spread the word about Rare Disease Day.** Share or repost information about in-person or virtual events to increase attendance.
- 7) **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 with friends and family, or tagging your favorite celebrity or elected official under our posts. Your efforts do not go unnoticed, and we rely on you to help bring awareness to the rare disease community.

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: bit.ly/RDD2023 **[Insert provided graphic or your own]**
2. #RareDiseaseDay is right around the corner and, **[I/my family/my organization]** will be wearing stripes to honor the #RareDisease community this year. For more information on how you can #ShowYourStripes, visit @RareDiseases website: bit.ly/RDD2023 **[Insert provided graphic or your own]**
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. Get involved: bit.ly/RDD2023 @RareDiseases **[Share a photo of building lit up in Rare Disease Day colors]**
4. The theme for #RareDiseaseDay is health #equity. Learn how you can get involved to help improve the health, well-being, access to care, and public awareness of the over 25 million Americans with a #RareDisease: bit.ly/RDD2023 @RareDiseases

On Rare Disease Day:

1. Today is #RareDiseaseDay & I am a proud **[member/supporter]** of the #RareDisease community. #ShowYourStripes & support the rare community today: bit.ly/RDD2023 **[Insert provided graphic or your own]**
2. Are you wearing stripes for #RareDiseaseDay today? #ShowYourStripes & join **[me/my family/my organization]** in spreading awareness for the #RareDisease community. You can support the community by getting involved now: bit.ly/RDD2023 **[Insert provided graphic or your own]**
3. Today is #RareDiseaseDay! **[share what you or your family/organization is doing for Rare Disease Day]** What are you doing to celebrate? #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: bit.ly/RDD2023

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]** & **@RareDiseases** in celebrating the rare community. Get involved: bit.ly/RDD2023 **[Insert provided graphic or your own]**
6. Today, we are illuminating **[our home/building/office]** in #RareDiseaseDay colors in honor of the #RareDisease community. Join **[me/my family/organization]** & #LightUpForRare! Get involved: bit.ly/RDD2023
[Share a photo of building lit up in Rare Disease Day colors]

Facebook/LinkedIn/Instagram:

Leading up to Rare Disease Day:

1. On #RareDiseaseDay **[I/my family/organization]** will be raising awareness for the rare disease community. Check out **[Tag NORD Facebook/LinkedIn/Instagram]** on Tuesday, February 28 to join the celebration. Learn how you can #ShowYourStripes: bit.ly/RDD2023 **[Insert provided graphic or your own]**
2. #RareDiseaseDay is just around the corner! **[I/my family/organization]** will be wearing stripes to honor the #RareDisease community. Learn how you can get involved in celebrating the rare community this year: bit.ly/RDD2023 #ShowYourStripes **[Insert provided graphic or your own]**
3. A disease is considered rare when it affects less than 200,000 individuals in the United States. **[I/my family/organization]** will be joining **[Tag NORD Facebook/LinkedIn/Instagram]** in celebrating and raising awareness for those affected by rare diseases. Learn how you can get involved: bit.ly/RDD2023 #ShowYourStripes #RareDiseaseDay **[Insert provided graphic or your own]**

On Rare Disease Day:

1. #RareDiseaseDay falls on the rarest day of the year, Tuesday, February 28, to represent the more than 25 million Americans impacted by #RareDiseases! #ShowYourStripes and join **[Tag NORD Facebook/LinkedIn/Instagram]** in support of the rare community. Learn how you can join the movement: bit.ly/RDD2023 **[Insert provided graphic or your own]**
2. 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: bit.ly/RDD2023 **[Insert provided graphic or your own]** **[Tag NORD Facebook/LinkedIn/Instagram]**
3. Did you know that over 25 million Americans are affected by a rare disease? Today, we join **[Tag NORD Facebook/LinkedIn/Instagram]** to celebrate and raise awareness for those affected by rare diseases.

Learn more about #RareDiseaseDay and how you can get involved: bit.ly/RDD2023 **[Insert provided graphic or your own]**

4. 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 Facebook/LinkedIn/Instagram]** as they bring light to the rare community! Learn how you can #ShowYourStripes: bit.ly/RDD2023 **[Insert provided graphic or your own]**
5. Today, we are illuminating **[our home/building/office]** in #RareDiseaseDay colors in honor of the #RareDisease community. Join **[me/my family/organization]** and **[Tag NORD Facebook/LinkedIn/Instagram]** and #LightUpForRare! Learn how to get involved: bit.ly/RDD2023 **[Share a photo of building lit up in Rare Disease Day colors]** **[Share a photo of building lit up in Rare Disease Day colors]**