# Rare Disease Day 2025 Social Media Toolkit

Rare Disease Day is an internationally recognized day and initiative to raise awareness, generate support and advocate for care and treatments for the 300 million people globally, including the 30 million Americans (about half of whom are children) who are living with a rare disease. It takes place annually on the last day of February. This year Rare Disease Day is February 28.

### Thank you for your support!

# **About #ShowYourStripes Campaign**

This year the National Organization of Rare Disorders (NORD) #ShowYourStripes campaign has a goal to raise awareness and show support of the rare disease community.

The zebra serves as the official mascot for rare disease patients. Historically, medical professionals were told that when they, "hear hoofbeats," they should expect a horse, not a zebra. We now know that 1 in 10 people in the U.S. have a rare disease. It might not be obvious when you look at us, which is one reason why we 'show our stripes, so people don't dismiss that some patients might be zebras. Every zebra's stripes are unique, mirroring the uniqueness and complexity of the more than 10,000 individual rare diseases, each of which impacts people in distinct ways. Dressing in zebra stripes is a way to "show up" for 30 million Americans living with a rare disease, hence why we say #ShowYourStripes.

Whether wearing zebra-print outfits, painting stripes on your face, or baking striped cookies, the goal is to celebrate individuality of all ages. We ask you to leverage your social media platforms (via stories or feeds) to bring awareness to the day, encourage your followers to show their stripes, and highlight those who embody the spirit of the day.

# **Official Hashtags**

Please use #RareDiseaseDay and #ShowYourStripes in every post and tag NORD (see tags based on each platform below).

### **NORD Social Media Channels**

#### rarediseaseday.us

Here are NORD's social media profiles for you to mention us in your posts:

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord\_rare

TikTok: @nord\_rare

### **Social Media Graphics**

NORD has created social media images you may use to raise awareness and start conversations online. Feel free to share these graphics along with our suggested language in this toolkit or to attach a graphic or photo of your own! We've provided some ideas below.

### CLICK HERE TO DOWNLOAD GRAPHICS FOR RARE DISEASE DAY 2025

## **Timing & Content Direction – When to Post**

### Between February 21-27 - Countdown to Rare Disease Day!

Rare Disease Day is coming up! You can lead up to Rare Disease Day by doing the following:

- Publish 1-2 posts asking your followers to get ready for Rare Disease Day on February 28 and participate in the #ShowYourStripes campaign by wearing stripes in support of the 30 million Americans with a rare disease.
- Feel free to share a sneak peek of what you have planned or different options you are thinking about that can be suggested to your audience.

### February 28 - Rare Disease Day!

It's showtime! Today is the day to share a photo and show your stripes by doing the following:

- Encourage your followers to share their striped spirit by tagging you and NORD along with using #ShowYourStripes and #RareDiseaseDay hashtags.
- Recognize followers that are embodying the campaign in their ways by sharing your stories.

## **Suggested Posts**

The following posts can be used across **Facebook**, **Instagram**, **LinkedIn**, and **Twitter/X** and customized as you see fit. For Instagram only, please remember to place the link in your bio or Linktree and direct users there, rather than placing the link in your post.

### The Countdown to Rare Disease Day

Did you know that zebras are the official symbol of rare diseases? #ShowYourStripes on February 28 for #RareDiseaseDay. Tag me as you get into the spirit (zebra or striped shirt, cap, sunglasses,

cookies, it's you to you!) And I may put you in my stories! Get involved on #RareDiseaseDay and learn how YOU can help today: bit.ly/rdd2025 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

I am counting down to #RareDiseaseDay on February 28! I will be wearing stripes to raise awareness of this important day! #ShowYourStripes by wearing a zebra cap, shirt, face paint or anything you'd like, then tag me and use the #ShowYourStripes hashtag and I may put you on my stories on Feb. 28. Learn more on how to get involved: bit.ly/rdd2025 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]



### Rare Disease Day - Friday, February 28, 2025

I am showing my stripes for **[NAME OF DISORDER]** awareness *OR* **[PERSON]** on #RareDiseaseDay. Rare diseases impact 30 million Americans. Use #ShowYourStripes, tag me and [insert correct NORD social channel] and I may recognize your spirit in my stories today! Learn more about rare diseases and get involved at <a href="https://bit.ly/rdd2025">bit.ly/rdd2025</a> **[ATTACH SELFIE/INDIVIDUAL PHOTO]** 

Today, I am joining the #ShowYourStripes campaign in honor of #RareDiseaseDay and the 30 million Americans living with a rare disease. Visit <a href="https://bit.ly/rdd2025">bit.ly/rdd2025</a> to learn about this rare day and get involved with [insert correct NORD social channel]. [ATTACH GRAPHIC OR PROVIDE YOUR OWN]

#### Did You Know?



Did you know rare diseases were so common, collectively? With more than 10,000 rare conditions, everyone likely knows someone impacted by a rare disease. This #RareDiseaseDay,

learn about the vast yet diverse rare community: <a href="mailto:bit.ly/rdd2025">bit.ly/rdd2025</a> [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

There is so much progress yet to be made into researching treatments for rare diseases. That's why we sponsor the National Organization for Rare Disorders on #RareDiseaseDay, February 28. Learn what you can do to help: <a href="https://discrete.com/bit.ly/rdd2025">bit.ly/rdd2025</a> [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

In 1983, the #OrphanDrugAct was passed and brought more resources toward the research, development, and distribution of #RareDisease therapeutics. 42 years later, we celebrate the continued progress and hope within the rare disease community! Learn how you can #ShowYourStripes in celebration: bit.ly/rdd2025 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

### **Show Your Stripes**



The zebra is the mascot for rare disease patients because, in medicine, zebras represent uncommon answers. One out of every 10 Americans has a rare disease. On February 28, #RareDiseaseDay, post a selfie with the hashtag #ShowYourStripes to share your rare story with others! [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

We show our stripes for **[NAME OF DISORDER]** awareness on #RareDiseaseDay. Rare diseases impact 1 in 10 Americans. Every individual and company can play a role in improving access to care and funding research for those with rare diseases. Visit <a href="bit:bit.ly/rdd2025">bit.ly/rdd2025</a> to learn more and #ShowYourStripes **[ATTACH GROUP PHOTO]** 

Today, we join the #ShowYourStripes campaign in honor of #RareDiseaseDay and the approximately 30 million Americans living with a rare disease. You are not alone! We encourage others to visit <a href="https://bit.ly/rdd2025">bit.ly/rdd2025</a> to learn about this especially rare day and get involved with us.

[ATTACH GROUP PHOTO]

I'm proud to show my stripes as a **[NAME OF DISORDER]** patient. Want to join me in making a difference? Support NORD and help create change for the rare disease community. Learn how you can help: <a href="https://disease.com/bit.ly/rdd2025">bit.ly/rdd2025</a> **[ATTACH GRAPHIC PROVIDED OR YOUR OWN]**