



Rare Disease Day 2024 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 1 in 10 Americans who are living with a rare disease. It takes place annually on the last day of February, which this year is February 29 – the rarest day of the year!

Why Show Your Stripes®?

When you “Show Your Stripes” you are helping to raise awareness and show support for millions of adults and kids in the U.S. and around the world with a rare disease or undiagnosed condition.

The zebra is the official mascot for rare disease patients. Historically, medical professionals were told that when they “hear hoofbeats,” they should not expect to see a zebra. In other words, look for the more common answer, a horse. Today, we know that 1 in 10 Americans is a zebra! It’s not always obvious to recognize or diagnose a person with a rare disease (a zebra). As a result, this can cause a delay in care and often negatively impacts a person’s quality of life or life expectancy.

It’s for this reason we ask our partners, individuals, groups and members of our community to “Show Your Stripes” leading up to and on Rare Disease Day and throughout the month of February and into early March.

Official Hashtags

We encourage you to use **#RareDiseaseDay** in every post.

When sharing a selfie, group photo, or personal story, use the hashtag **#ShowYourStripes**.

If you are lighting up a monument in honor of Rare Disease Day, use **#LightUpForRare**.

Official Website

The official go-to destination for Rare Disease Day in the U.S. is www.rarediseaseday.us. It's here where you will find:

- National and statewide events open to participation
- A “Faces of Rare” interactive dedication photo and storyboard wall
- Inspirational stories
- “Show Your Stripes” Community, School and Work Activation ToolKits
- Light Up For Rare International Campaign of Lights: How to participate
- How to participate in local and state grassroots advocacy with NORD’s Rare Action Network®
- Rare Disease Facts & Press Kit
- Official Gear and Merchandise

NORD Social Media Properties

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

Facebook: [@NationalOrganizationforRareDisorders](https://www.facebook.com/NationalOrganizationforRareDisorders)

Twitter: [@RareDiseases](https://twitter.com/RareDiseases)

LinkedIn: [@NationalOrganizationforRareDisorders](https://www.linkedin.com/company/national-organization-for-rare-disorders)

Instagram: [@nord_rare](https://www.instagram.com/nord_rare)

TikTok: [@nord_rare](https://www.tiktok.com/@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 2024](#)



Suggested Posts

The following posts can be used across **Facebook**, **Instagram**, **LinkedIn**, and **Twitter/X** and customized as you see fit. They have been grouped according to topic so you can choose what is most applicable to you. *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.*

Rare Disease Day Is Coming Up / It's Rare Disease Day



- February 29 is #RareDiseaseDay, the rarest day of the year! As one of 300 million people worldwide and their loved ones affected by a rare disease, I encourage you to learn about our journeys and how YOU can help us today: bit.ly/RDD2024 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]
- We're counting down to #RareDiseaseDay on February 29! Get to know the faces of some of the 30 million Americans living with rare diseases, as well as ways you can get involved, on the National Organization for Rare Disorders (NORD) website: bit.ly/RDD2024 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

- Today is #RareDiseaseDay, the rarest day of the year! Celebrate the 1 in 10 Americans who live with a rare disease or disability today by reading some of their powerful stories collected by the National Organization for Rare Disorders (NORD): bit.ly/RDD2024 **[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 29, #RareDiseaseDay, post a selfie with the hashtag #ShowYourStripes to share your rare story with others! **[ATTACH GRAPHIC PROVIDED OR YOUR OWN]**
- I show my stripes for **[NAME OF DISORDER]** awareness on #RareDiseaseDay. Rare diseases impact 1 in 10 Americans. We need you to understand us and how you can help. Visit bit.ly/RDD2024 to learn more and spread the love. #ShowYourStripes
[ATTACH SELFIE/INDIVIDUAL PHOTO]
- Today, we join the #ShowYourStripes campaign in honor of #RareDiseaseDay and the 1 in 10 Americans living with a rare disease. You are not alone! We encourage others to visit bit.ly/RDD2024 to learn about this especially rare day and get involved with us.
[ATTACH GROUP PHOTO]

Donate in Honor of Rare Disease Day



- I made a donation to the National Organization for Rare Disorders in honor of #RareDiseaseDay, which is on the rarest day of the year, February 29! No condition is too rare for us to solve together. I encourage you to learn more and join me today: bit.ly/RDD2024 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]
- In honor of the rarest day of the year, #RareDiseaseDay, February 29, please make a donation to help the 1 in 10 Americans like me with rare, often invisible or misunderstood conditions. There is so much to be hopeful for, but we're all in this together! bit.ly/RDD2024 [ATTACH GRAPHIC PROVIDED OR YOUR OWN]

Did You Know?



- Did you know rare diseases were so common, collectively? With more than 7,000 rare conditions, everyone likely knows someone impacted by a rare disease. This #RareDiseaseDay, learn about the vast yet diverse rare community: bit.ly/RDD2024



- There is so much progress yet to be made into researching treatments for rare diseases. This is a public health issue in every community. Learn what you can do to help on #RareDiseaseDay, February 29, the rarest day of the year: bit.ly/RDD2024