



## Social Media Toolkit

The zebra is the official symbol of rare diseases in the United States and is noted for its black and white stripes, which are central to its uniqueness. Everyone has his/her own stripes, those characteristics that make each individual distinct. While each of the more than 7,000 rare diseases are unique, there are many commonalities that unite the rare disease community. In the spirit of increasing awareness regarding rare disease issues, raising the profile of the rare disease community at large and celebrating Rare Disease Day, this year NORD is promoting specific ways that individuals, organizations and groups can “show their stripes.”

**One easy way that you can show your stripes is by sharing messages on social media!**

Join us and raise awareness for the rare disease that you are impacted by and for the community in general by sharing messages on social media. This toolkit includes helpful general tips, sample social media posts to share, graphic design templates that you can upload onto social media, and the proper hashtags and profiles to tag.

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## Getting Started

### Social Media Properties

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

**Facebook:** @NationalOrganizationforRareDisorders; @RareDiseaseDay.US

**Twitter:** @RareDiseases; @RareDayUS

**LinkedIn:** @NationalOrganizationforRareDisorders

**Hashtags:** #ShowYourStripes, #RareDiseaseDay

### Graphic Design

The link below will direct you to a compressed zip folder that contains graphic design elements that you may feel free to share on social media. The folder will automatically download onto your computer when you click the link below.

**[Download Rare Disease Day Graphics](#)**



## Helpful Tips for Social Media

- **Attach an image to your post** – feel free to use one of the assets that we’ve provided on page 2 or get creative! Have fun with the theme, “Show Your Stripes,” on your account and in your posts using graphic elements.
- **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, and beyond**– are there contacts in your social network who you know would like to get involved with Rare Disease Day? Tag them in your posts and encourage them to participate. Have ideas about public figures, leaders, celebrities and others who you may not know but think would be interested in your message? Tag them!
- **Include a call to action** - use clear wording in your posts, especially if there is something you’d like your followers to do (i.e. “Show your support! Wear stripes on Rare Disease Day and post a pic with the hashtag #ShowYourStripes).
- **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 the most effective.



## Posts to Share on Your Profiles

### Twitter

- Every stripe has a story. I have \_\_\_\_\_, one of the 7K+ #rarediseases. #ShowYourStripes #RareDiseaseDay {upload photo of yourself}
- This year for #RareDiseaseDay, #NORD (@RareDiseases) is asking the #raredisease community to #ShowYourStripes. This is me. I have \_\_\_\_\_, a #raredisease. {upload photo of yourself}
- My stripes are rare. I have \_\_\_\_\_, a #raredisease. #ShowYourStripes #RareDiseaseDay {upload photo of yourself}
- Everyone has their own unique stripes. I'm wearing stripes for #RareDiseaseDay - do the same and spread the word! #ShowYourStripes (upload a photo of yourself, your group or organization wearing stripes)
- Did you know that there are 25-30 million Americans living with #rarediseases? #ShowYourStripes #RareDiseaseDay {upload graphic design element}
- **SHARE YOUR STORY IN 280 CHARACTERS OR LESS:** What is your name, the rare disease you are impacted by, the state that you live in? Share a photo of yourself and use #ShowYourStripes #RareDiseaseDay



### Facebook/LinkedIn/Instagram

- Every stripe has a story. I have \_\_\_\_\_, one of the more than 7,000 rare diseases. This year for #RareDiseaseDay, @NationalOrganizationforRareDisorders is asking the rare disease community to show our stripes. This is me. **INSERT INFORMATION ABOUT YOUR RARE DISEASE AND HOW IT IMPACTS YOUR DAILY LIFE.** Please join me in recognizing Rare Disease Day on February 28, 2019. It's a day that is very important to me and the 25-30 million Americans impacted by rare diseases. #ShowYourStripes {upload photo of yourself}
- My stripes are rare. I have \_\_\_\_\_, a rare disease. This year, I am showing my stripes for #RareDiseaseDay, a day that is very important to me and the 25-30 million Americans impacted by rare diseases. #ShowYourStripes {upload photo of yourself}
- Everyone has their own unique stripes. I'm/we are wearing stripes for #RareDiseaseDay to raise awareness and show support for the 25-30 million Americans impacted by rare diseases. Please do the same and spread the word! #ShowYourStripes #RareDiseaseDay upload a photo of yourself, your group or organization wearing stripes)
- Did you know that there are 25-30 million Americans who are impacted by rare diseases? A rare disease is one that affects fewer than 200,000 individuals in the United States. There are currently over 7,000 identified rare diseases. On Rare Disease Day, we come together to show our stripes and raise awareness! Join us! Learn more at [rarediseaseday.us](http://rarediseaseday.us) #ShowYourStripes #RareDiseaseDay {insert graphic design element}



## Other Social Media Activities

In addition to sharing the suggested posts and graphic design elements on your social media channels, consider using social media in the following ways for Rare Disease Day:

- **Spread the Word:** Share information about an in-person event to help spread the word and increase attendance
- **Change Your Profile Pic:** Use our Facebook Profile Picture Frame from now until February 28, 2019 \*hyperlink when ready\*
- **Commit Your Feed:** Devote your social media profiles to rare diseases during the month of February by committing to sharing a post about rare disease every day. Whether it be your own post, photos from our graphic design elements on page 2, or sharing news articles, your continuous posts will help to raise awareness for rare diseases.
- **Go Live!** Go live on Facebook for a few minutes or more to share your personal rare disease story. Going live is a popular way to get attention on Facebook as your friends will be notified when you do it. In order to be prepared before going live, you may want to plan out your talking points in advance.
- **Increase Engagement:** NORD and its Member Organizations will be posting about Rare Disease Day frequently leading up to and on the big day. Make those posts go further by not only sharing them, but tagging your friends and others. Here are some ways that you can help increase engagement on posts:
  - Comment with what rare disease you are impacted by
  - Comment and tag a friend and ask them to share the post to raise awareness
  - Share the post and tag your favorite celebrity in the post to let them know about Rare Disease Day
  - Comment and tag your elected officials
  - Share the post and tag 10 friends who may not know about rare diseases