

2024

Rare Disease Day[®]

School & Campus Playbook



NORD[®]
National Organization
for Rare Disorders



Join Us on Rare Disease Day

February 29, 2024



RARE Is Not Rare.



More than 30 million Americans — 1 in 10 people — are living with a rare disease right now. They are our loved ones, friends, neighbors, colleagues, and classmates. Approximately half of them are children.

Rare Disease Day is a global awareness day to generate support for everyone who is on a rare medical journey. It takes place annually on the last day of February, which this year is February 29th - the rarest day of the year.

The National Organization for Rare Disorders (NORD®) is the official partner for Rare Disease Day in the U.S., working with volunteers, organizations and schools nationwide through our **Show Your Stripes®** campaign.

Awareness is most important closest to home. Rare Disease Day is an opportunity for rare kids and adults to build the supportive, understanding friendships they need to thrive.



What's in This Playbook

Inside this School & Campus Playbook, you'll find everything you need to understand Rare Disease Day and how to bring the fun to your campus. We have ideas and resources for both K-12 and colleges and universities, including activities, school curriculum, and sample social media content.

Your participation means so much to our movement and to the 1 in 10 people living with a rare disease where you live.

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Why

Show Your Stripes®

Do you know why the zebra is the official mascot of the rare disease community?

Historically, medical professionals were told when they “hear hoofbeats,” they should think horses, not zebras. In other words, think of more common explanations for a patient’s symptoms. Now, we know that 1 in 10 Americans is actually a zebra!

Show Your Stripes® is our rallying cry, a way for millions of people with rare conditions, along with our loved ones and medical providers, to come together in a global awareness movement.

It might not be obvious when you look at us, so we **show our stripes** on Rare Disease Day to raise awareness and start conversations that help others learn about rare diseases and the challenges that come with them.



Stripe Out Your School (K-12)

Help educate those around you on Rare Disease Day by striping out at school.

- Ask for permission to post Rare Disease Day posters or lawn signs around the school to raise awareness.
- Encourage other students, teachers, and administrators to wear stripes on Rare Disease Day to start a school-wide conversation. You could even pair it with a dress-down day and collect donations!
- Set up a table to pass out information and stickers at a school event taking place on or around February 29th (e.g. a sports event or assembly) or in a high-traffic area.
- Does your school have a newspaper or journalism club? Write an article about Rare Disease Day and feature the story of someone you know with a rare disease.
- Host a bake sale with zebra-themed cupcakes and collect donations.



**The possibilities are endless-
Get creative!**

Stripe Out

Your College Campus

Show Your Spirit

Show your Rare Disease Day support by spreading awareness to those around you! Fly a zebra flag in your window, outside your sorority or fraternity house, or use chalk to decorate a driveway or parking lot with zebra stripes to share your Rare Disease Day spirit and inspire your neighbors to get involved.



Stripe Out Your Campus

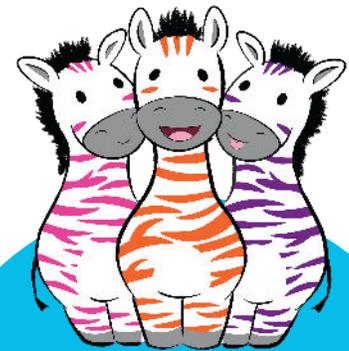
Why stop at your dorm or campus apartment? Meet with your school administrators to launch a campus-wide 'Show your Stripes' campaign on crosswalks, buildings, lamp posts, and more. If stripes aren't an option, **Light Up for Rare** is a great way to rally your school community by lighting up landmarks and buildings with Rare Disease Day colors on February 29th.

Stripe Out

A Campus Event

Is there a school event on February 29th? This could be anything – truly anything!

From a big football game to a pep rally, all-school assembly or club meeting, work with the organizer to encourage attendees to wear stripes to show their support of Rare Disease Day.



Zebra socks, bows, headbands, or face paint will make a statement!



Show Your (Digital) Stripes

Social media is an incredible tool for spreading the word about #RareDiseaseDay, too!

You can Show Your Stripes® in many ways from the comfort of your home:



Share Your Rare Disease Story: Do you have a rare disease? Or a family member with a rare disease? Leverage one of our templates to share your story on social media.



Social Stripe Out: Post a selfie wearing stripes on social media and challenge 10 people to do the same (to represent the 1 in 10 people living with a rare disease).



Get Creative: Gather your friends, teammates, teachers, and campus community to make a video, photo album, or other creative expression of what it means to Show Your Stripes®.



However you choose to Show Your Stripes®, don't forget to tag us on social media and use the Rare Disease hashtags. See the next page for more info!

Make Noise on Social Media

Leading up to and on Rare Disease Day, NORD® will be looking out for posts that capture communities Showing Their Stripes.

Tag NORD®'s social media handles and hashtags in your stories and posts to be featured on our social media channels.

 Facebook:
@NationalOrganizationforRareDisorders

 Twitter:
@RareDiseases

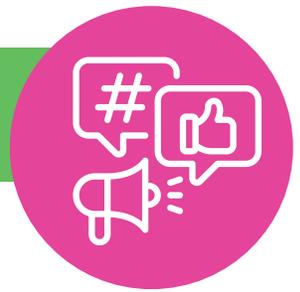
 LinkedIn:
@NationalOrganizationforRareDisorders

 Instagram:
@nord_rare



NORD® has created social media images you may use to raise awareness and start conversations online. [Access here.](#) Also find sample social media posts on pages 10-13 of this playbook.

Sample Social Media Posts



On Rare Disease Day...

Share a photo of your staff and students wearing stripes along with one of the following messages:

- Today is #RareDiseaseDay and [University/School/Sorority or Fraternity/School Club] is a proud supporter of the #RareDisease community! #ShowYourStripes and support the 1 in 10 Americans with a rare disease today: rarediseaseday.us.
- We striped out [University/School/ Sorority or Fraternity/School Club] in honor of #RareDiseaseDay, the rarest day of the year! Did you know rare is not so rare? 1 in 10 Americans lives with a rare disease. #ShowYourStripes to show your support: rarediseaseday.us
- Happy #RareDiseaseDay from [University/School/Sorority or Fraternity/School Club] in [Town or City]! We're proud to show up for the 1 in 10 people in our community who live with rare diseases and disabilities. Learn more: rarediseaseday.us #ShowYourStripes
- Are you wearing stripes today for #RareDiseaseDay? Join [University/School/ Sorority or Fraternity/School Club] as we raise support for the rare disease community by getting involved now: rarediseaseday.us #ShowYourStripes



We are Here to Help

NORD® offers a press kit and downloadable resources including infographics and images to help you support Rare Disease Day.

Use these resources as part of an intranet awareness campaign or in conjunction with your Rare Disease Day event.

Tap into our expertise. We're here to help.
Email marketing@rarediseases.org with questions.

[DOWNLOAD ALL
RESOURCES HERE](#)



Press Kit



School Curriculum



Light Up for Rare Guide



Lawn Signs



Posters



Our Mission & Impact

For more than 40 years, the National Organization for Rare Disorders (NORD[®]) has served as a trusted voice and leading patient advocacy organization fighting to improve the lives of the 30 million Americans with rare diseases by driving advances in care, research, and policy.

THE BURDEN OF RARE DISEASES

Too often, rare patients and families are left isolated and without answers or support for their medical needs. **It doesn't have to be that way.**

NORD provides support for all patients and their families with rare diseases. We partner with patient communities, clinicians, world-class medical institutions, researchers and policymakers to provide resources, education and assistance.

Together, we are united by a single purpose – to solve the greatest challenges facing the rare disease community.





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www.RareDiseaseDay.us