2027 Rare Disease Day®

Community Playbook







NORD®
National Organization for Rare Disorders

RARE DISEASE DAY®

Join Us on Rare Disease Day

February 28, 2027

RARE DISEASE DAY®

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 28th.

The National Organization for Rare Disorders (NORD®) is the official partner for Rare Disease Day in the U.S. We actively work with volunteers, organizations and schools nationwide to participate in our Rare Disease Day **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 Community Playbook, you'll find everything you need to understand Rare Disease Day and how to bring the fun to your town or city, including activities, event ideas, 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 Community

Stripe Out Your Home or Neighborhood

Show your Rare Disease Day support by spreading awareness to those around you! Fly a zebra flag in your yard or use chalk to decorate your driveway with zebra stripes to share your Rare Disease Day spirit and inspire your neighbors to get involved.



Stripe Out Your Town

Why stop at your home and neighborhood? Meet with your town administrators to launch a town-wide Stripe Out 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 town behind Rare Disease Day by lighting up landmarks and buildings with Rare Disease Day colors on February 28th.

Stripe Out
A Community Event

Is there a town event on February 28th? This could be anything – truly anything!

From your child's little league baseball game to a town hall meeting or annual block party, work with the host/coach 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!





Host Your Own Rare Disease Day Event

In-person (and virtual) events are an effective way to educate and engage community members and grow our movement.
Here are some tips to get started:

- Get creative, but make sure that your event is hosted at a location that's accessible – and inclusive – to all.
- From a zebra-themed bake sale outside your grocery store to a 5K run or walk, there are no limitations to how long (or short) your event could be – tip: make it a timeframe that you can be there to ensure it runs smoothly.
- Invite a local speaker to represent the rare community and/or share their personal story at your event.
- Secure a high traffic location with table/chair, such as at a school/athletic event, outside a coffee shop and share information, RDD stickers, etc. Invite 10 friends and family members – to represent the 1 in 10 individuals that has a rare disease – and challenge them to share information.
- Don't forget to take photos and videos and share on your social media channels!



Show Your (Digital) Stripes

Want to Show Your Stripes® from the comfort of your home?
No problem – here's how you can get in the spirit:

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 encourage your friends, family, and others to do the same.



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



Email Your Legislator(s): Use our outreach template to reach out to your local and state representatives to recognize Rare Disease Day and the needs of their rare community.



However you choose to Show Your Stripes®, don't forget to tag us on social media and use the #RareDiseaseDay 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 yourself or your group wearing stripes with one of the following messages:

- Happy #RareDiseaseDay from [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. #ShowYourStripes and get involved with us: rarediseaseday.us

- Today is #RareDiseaseDay and [Town Name] is proud to support our #RareDisease community! #ShowYourStripes and support the 1 in 10 Americans living with a rare disease today: rarediseaseday.us

- We striped out [Town or Neigborhood Name] 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

- Are you wearing stripes today for #RareDiseaseDay? Join [Town Name] 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



Start a Fundraiser



Light Up for Rare Guide



Lawn Signs



Posters

NORD®

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