2027

Rare Disease Day®

Corporate Playbook







NORD®
National Organization for Rare Disorders

RARE DISEASE DAY®

What's in This Playbook

The National Organization for Rare Disorders (NORD®) invites your company, leadership, and staff to participate in this year's Rare Disease Day — an international awareness day celebrated annually on the last day of February, which is February 28.

A rare disease is any disorder that impacts fewer than 200,000 Americans each year. There are more than 10,000 rare diseases, many of which you have heard of—such as childhood cancers—and many of which you may not know about. And while individual patient populations may be small, when considered altogether, 1 in 10 Americans lives with a rare disease. We share the struggle of longer waits for diagnoses, higher health care costs, and feelings of misunderstanding and isolation.

Your participation during Rare Disease Day 2027 can make a world of difference for the individuals in your staff, city, and industry living with or caring for others with rare diseases.

Inside this Corporate Playbook, you'll find everything you need to understand Rare Disease Day and the role your company can play as an ally. This includes ideas for events, corporate giving resources, and sample social media content you can use on February 28.

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Join Us on Rare Disease Day

February 28, 2027

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.

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.

How You Can Join Us

Whether it's empowering employees to share their stories, creating a cause marketing campaign or simply promoting messages and stories, this playbook is meant to provide everything your company needs to get started.



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.



Ways to Show Your Stripes®

Promoting the **Show Your Stripes®** call to action online is a turn-key, efficient and effective way to engage consumers, employees and partners on Rare Disease Day.



- Challenge your colleagues to wear stripes in solidarity with the rare disease community on February 28th.
- Ask them to take a selfie in their stripes and post it to social media with the hashtags #ShowYourStripes and #RareDiseaseDay.
- Repost these striped selfies on your company's social media pages or internal channels.

- Highlight a specific disease or colleagues in your social media. "We show our stripes for the 10 million people battling....."
- Provide a small donation for each post or like or repost, e.g., "We'll donate $X for each post"
- Enlist influencers in your company's network to activate on Rare Disease Day via their channels.
- Be sure to include this **link** for consumers to donate to NORD.

Engage on Social Media

A great way to Show Your Stripes® is by joining the conversation on social media.

Here are some of NORD®'s social media profiles and hashtags. You can mention us in your posts or refer your followers to our social channels for more information on Rare Disease Day:

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 14-16 of this playbook.

Host a Rare Disease Day Event

Either virtually or in-person, events are an effective way to educate and engage employees on issues facing the rare disease community.

Host a lunch & learn or internal event for employees to connect and learn more about rare disease issues.



Invite an employee or local speaker to share their personal story.



Work with CSR, HR and Employee Resource Groups to create & promote a company-wide awareness effort on Rare Disease Day.



Light Up for Rare. Each year, landmarks and buildings across the world are illuminated in the RDD colors. Light Up your headquarters to create awareness and show your support.



Encourage Workplace Giving

Many companies use Rare Disease Day as an opportunity to promote workplace giving and offer company matches.



Rally employees by creating a fundraising goal. For example, set a goal of raising $10,000 to signify the 1 in 10 Americans that have a rare disease.



Match employee donations as a way to further participation and increase donations.



Work with HR and Employee Resource Groups to promote the effort through intranet and posters in key locations within the office.



Encourage ERGs to host company-wide event to educate & engage their colleagues about rare diseases.

Recognize employees who donate via Intranet.

Access digital resources and sample posts **HERE.**

Show Your Stripes® Fundraising Challenge



Another fun way to raise support is adding some light competition. That's where the Show Your Stripes® fundraising challenge comes in.

How it works:

- Individual employees or entire departments within the company compete to see who can raise the most funds on Rare Disease Day.
- Employees tap their family, friends and social networks with the Show Your Stripes ® message and donation ask.
- NORD® provides personalized urls to track donations.
- The company then makes a donation to the winning individual or department.

Create a Cause Marketing Campaign

Cause Marketing is a highly effective way for companies to tap their consumers and customers to raise support for NORD®.

And there's a range of ways to implement cause marketing based on your company's approach and sales process.

Another benefit of cause marketing, is it can be done on Rare Disease Day and relevant times throughout the year.

Round-up or donate at checkout

Percent of Sales Donation

Leverage Loyalty Program







Round-up or Donate at Checkout

This is the most effective and efficient way to engage consumers and employees to raise funds. Research shows that consumers prefer point of sale donations to other types of cause marketing efforts.*

- Donation is prompted by employee, POS signage and credit card pin pad prompt
- Sample Message: **Defeat Rare Diseases.**
- Rounding up (consumer rounding up their purchase to the nearest dollar) is the most popular approach with consumers
- Add $1, $3, or $5 is the second most popular
- Don't forget you can do the same via online check out and on your company's app
- Use of credit card keypads is more effective than employee prompts
- Train employees and offer them incentives



*Source: Children's Miracle Network Hospitals Point-of-Sale Research 2022

Percent of Sales Donation

A company offers a donation to NORD® tied to the sale of a featured product. There are wide variations within execution and how a donation is determined.

What to Know

- Companies typically trigger donations in one of four ways:
  - Set price per item ($1 donated per item)
  - Buy one, give one
  - % of sales
  - % of net profit

- Critical to be Clear to meet BBB Standards

  Optimal: $x of each sale is donated

  Ok: % of sales

  Avoid: “Net proceeds” or “portion of proceeds”

- Opportunity to tie with Rare Disease Day or other moments like Caregiver Awareness Month



Leverage Your Loyalty Program

Increasingly companies are integrating their support of a social cause with their consumer loyalty programs. It's an effective way to reward consumers and raise dollars.

What This Looks Like Includes

- Providing loyalty points or special offers when a consumer donates to NORD® via the loyalty program app
- Enabling consumers to donate to NORD® by rounding-up their purchases on an ongoing basis. In return, the company provides additional loyal points to the consumer.





Sample Social Media Posts

On Rare Disease Day:

Sample Social Media Posts

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

- Today is #RareDiseaseDay and [our organization] is a proud supporter of the #RareDisease community. 1 in 10 Americans lives with a rare disease. #ShowYourStripes and and get involved with us on the rarest day of the year: rarediseaseday.us

- Happy #RareDiseaseDay from the team at [our organization]! 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 today: rarediseaseday.us

- Are you wearing stripes today for #RareDiseaseDay? Join [our organization] and @RareDiseases as we raise support for the rare disease community by getting involved now: bit.ly/RDD2026 #ShowYourStripes

- We striped out our office 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





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



Virtual Background



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.

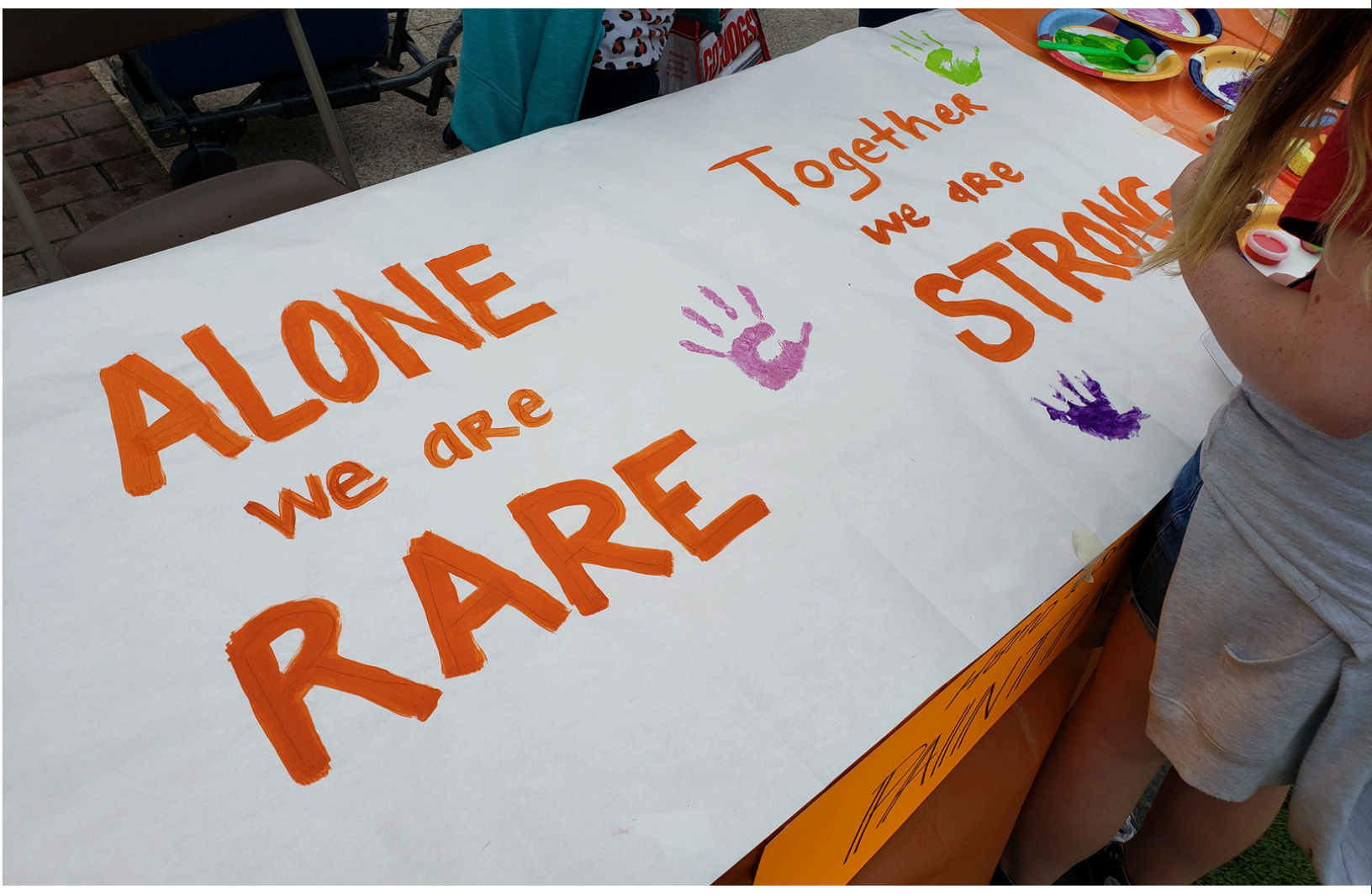
THE BURDEN OF RARE DISEASES

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.



NORD®
National Organization
for Rare Disorders

www.RareDiseaseDay.us