





Rare Disease Day® 2027

Medical Community Playbook

Information & Ideas for Hospitals, Researchers, and Clinicians

NORD®
National Organization for Rare Disorders

RARE DISEASE DAY®

What's in This Playbook

Your participation during Rare Disease Day® 2027 can make a world of difference!

As a clinician, researcher, allied health professional, or faculty member, you engage with a broad audience made up of your colleagues, your patients and their families, and the public.

In this playbook, we'll share ways to rally these audiences to learn more and do more on Rare Disease Day!

We especially recognize the amazing faculty, staff, and trainees across our NORD Rare Disease Centers of Excellence Network for sharing their rare disease day events and providing inspiration for this playbook.

Get Started With:

- Activities for Children & Families
- Activities for Faculty, Clinicians, Healthcare Professionals, & Researchers
- Activities for Engagement with the Public
- Social Media Engagement
- Funding Opportunities
- NORD/Rare Disease Day information, printouts and contacts

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. 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.

Why Show Your Stripes®

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

Historically, medical students in the United States were told when they "hear hoofbeats," they should think horses, not zebras. In other words, think of common diseases as the likely cause of a patient's symptoms.

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

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.



Engaging Families



Host a Table or Display in your clinic or hospital lobby!	• Complement your set up with zebra related items like inflatables, plushies, other giveaways, and food
Have a Fun Family Day to celebrate families caring for a rare disease patient!	• Provide activities for children and adults, such as coloring and crossword pages, DNA related activities, a prize wheel, or Rare Disease Day trivia! • Fun things to do can include a magic show, face painting, a “tattoo” artist, a book reading, or a documentary screening.
Host an Education Day for patients and families to learn more about resources, advancements, and research in the Rare Disease Field.	• Invite speakers from across your institution, clinic, community organizations and/or patient advocacy groups to speak on their work and resources.

Rallying Faculty, Clinicians, & Healthcare Professionals



In-person (and virtual) events are an effective way to educate and engage a range of medical stakeholders including faculty, clinicians, researchers, and trainees.

Here are some thoughtstarter ideas:

Organize a Rare Disease-focused Grand Rounds or Case Conference.	• If you have a regularly scheduled educational rounds or conference within your department, pick a date near Rare Disease Day to highlight rare disease cases, innovations, or research.
Host a Rare Disease Day symposium or networking event.	• Consider having faculty and trainees submit posters. • Invite clinicians/researchers in the field to speak. • Invite members of your state's RDAC to the event to provide updates on policy initiatives. • Highlight stories from families or patient advocacy groups.
Screen a Rare Disease documentary followed by a discussion.	• Some rare disease groups have documentaries on their rare condition, highlighting stories of several families. • Host a screening, invite the filmmakers or patient group leaders and hold a discussion or Q&A after.

Hosting A Rare Disease Day Event for the Public

Where

- A zoo, brewery, mall, park, public gathering space – anywhere that people can get to or a place with a lot of foot traffic!

What To Do

- Set up a table or display to share rare disease information. Offering zebra themed goodies and activities will help attract attention.
- Have a more organized event: have a couple of booths with different information and activities for children, families, and adults.

How To Create Awareness

- Connect with a local TV or Print News to announce the event along with sharing:
  - A patient/family story
  - Clinical advancements in a specific rare disease clinic at your hospital
  - New research completed at your site
  - Advocacy work of a local patient advocacy group
- Hand out Event flyers to patients & families in clinics.
- Share event details with faculty & staff.
- Reach out to Child Life and other Pediatric Departments.
- Post Event flyers around the hospital.

Finding Funding Opportunities

Hosting an event can be expensive – Where can I look for funding, sponsors, or donations?

- Department Funding
- Hospital Event Funding
- Support from Hospital Leadership
- Outside (Charitable Funds)
- Pharmaceutical Company/Industry Charitable Funds
  - Application process
  - Be mindful of hospital regulations regarding pharmaceutical company presence at events (if that is requirement of receiving funding)
- Donations: From Local Companies

Showing 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!

Making 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.

@NationalOrganizationforRareDisorders

@RareDiseases

@NationalOrganizationforRareDisorders

@nord_rare

Social Media Accounts to consider [Twitter, Facebook, Instagram]:

- Main Hospital System
- Department
- Medical School
- Clinic
- Partnering with Student Groups (if appropriate – can students attend the event?)



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.

Social Media Resources

NORD has made it fun and easy to increase awareness and engagement on Rare Disease Day... through two social media toolkits.

We have posts, images, and content, everything you need to get started!

Get Started Here!

- Downloadable Materials
- Rare Disease Day Toolkit



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