

Making An Impact On Rare Disease Day

There are over 300 million men, women and children worldwide living with one or more of over 7,000 identified rare diseases. Do you or a family member have one or know someone who does?

SOME QUICK FACTS TO THINK ABOUT

- » 1 in 20 people will live with a rare disease at some point in their life.
- » More than 90% of rare diseases are without an FDA approved treatment.
- » Many rare diseases result in the premature deaths of infants and young children or are fatal in early childhood.
- » Over 500 types of rare cancers.
- » All pediatric cancers are rare.

HISTORY BEHIND RARE DISEASE DAY

The first Rare Disease Day was on February 29, 2008 in Europe. Being a leap year, it brought a special significance to the cause since it is a rare date that happens once every four years. The United States joined in 2009 lending support with over 100 other countries to bring attention to this cause and share its impact on patient's lives. Now, each year on the last day of February, the rare disease community comes together to raise awareness on Rare Disease Day.

ZEBRA: THE OFFICIAL US MASCOT OF RARE DISEASE DAY

Forget birds, bees, or even bears—the zebra is the official US mascot for those suffering from a rare



disease. With its distinctive markings symbolizing both individual uniqueness and community strength. Individuals, organizations, and groups are encouraged to 'show their stripes' in support of Rare Disease Day in a variety of ways.

5 WAYS TO SHOW YOUR STRIPES ON SUNDAY, FEBRUARY 28, 2021

- 1. Share your story with <u>https://rarediseases.org/</u> <u>shareyourstory/</u> and inspire others with your personal experiences.
- 2. Wear striped gear and share on social media with the hashtag #showyourstripes, #rarediseaseday
- 3. Check out your state's report card (<u>https://</u><u>rareaction.org/resources-for-advocates/state-profiles/</u>) to see how your state is stacking up. If you don't like what you see, reach out to your state's representatives and let your voice be heard.



HEALTH BULLETINS



- 4. Encourage your company or organization to collaborate on a major striping concept for Rare Disease Day. For example, wrap a train car in stripes, drape your workplace's lobby in striped banners, light up the exterior of a building with stripes or arrange to take a photo of a large number of you and your colleagues assembled in stripes.
- 5. Print and color this zebra coloring sheet (<u>https://</u><u>rarediseases.org/wp-content/uploads/2019/01/</u><u>nord-rddus-zebra-coloring-sheet.pdf</u>) and share your art on social media.

