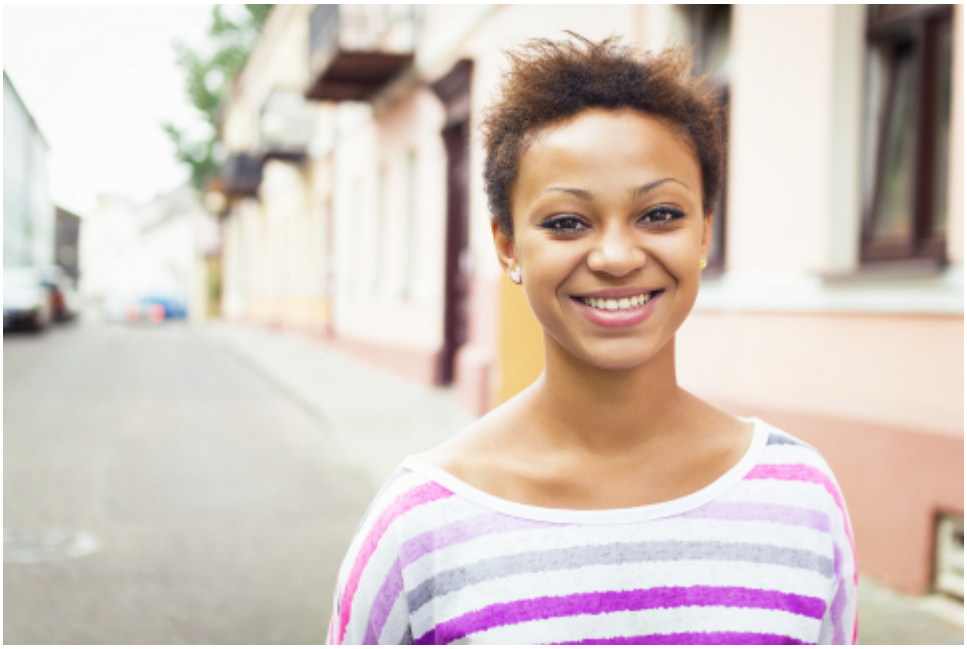
NICHQ National Institute for Children's Health Quality

Each year, the last day of February is dedicated to raising awareness about rare diseases, defined as a condition that affects fewer than 200,000 people. Despite the fact that many rare diseases go undiagnosed and no cure exists for a majority of rare diseases, progress is being made to ensure that children and families are receiving the individualized support and care needed to reach their optimal health. Keep scrolling to learn how you can participate in Rare Disease Day with NICHQ!

Celebrate Rare Disease Day

Use your organizational and personal social media to advocate for equity for those born with rare diseases. We've developed **an online social media toolkit** with graphics, images, and sample posts sharing key statistics and facts that illustrate the impact rare diseases have on more than 25 million American families.

Follow us on **Facebook**, **Twitter**, and **LinkedIn** for posts and resources throughout the month.



Share Your Story

Are you a parent of a child with a rare disease, someone living with a rare disease, or a care provider to people with rare disease? Sharing your story can help more people learn about rare diseases and why they deserve attention.

Submit your story **here.**

Improve Care for Patients

1 in 20 people will live with a rare disease at some point in their life. Read the articles below for strategies that address the needs of those living with rare diseases.

- Improving Transitions in Care Saves Lives: These strategies can guide transition care for young adults with sickle cell disease to improve health outcomes throughout adulthood.
- Explore HRSA's New Newborn Screening Information Center: Designed to increase awareness, knowledge, and understanding of newborn screening and genetic conditions.
- Continuing Sickle Cell Disease Care during the COVID-19 Pandemic: People with rare diseases, such as sickle cell disease, have been more vulnerable to the COVID-19 impact. Here's how providers and advocates have remained nimble to ensure that comprehensive and consistent care is maintained throughout the pandemic and beyond.

NICHQ Initiatives Focused on Rare Diseases

Rare As One Network Workstream Facilitation: NICHQ is supporting the launch of patient-centered research networks by facilitating topical workstreams with grantees from the Rare As One Project (RAO).

Content Development for Newborn Screening Clearinghouse: To increase awareness, knowledge, and understanding of newborn screening and genetic conditions, NICHQ partnered with Genetic Alliance to develop, revise and deliver general, state-specific and condition-specific newborn screening website content.

Disseminating Results: Missed Sickle Cell Disease Clinic Appointments and the Health Belief Model: NICHQ disseminated findings to a network of sickle cell disease stakeholders on improving routine appointment attendance among Sickle Cell Disease patients.

Sickle Cell Disease Treatment Demonstration Regional Collaborative Program National Coordinating Center: NICHQ works with five regional teams from across the country to improve coordination and service delivery for individuals living with sickle cell disease, enhance access to services, and improve and expand patient and provider education.

Interested in learning more about the Rare Disease Day movement?
Visit the official Rare Disease Day campaign page for more resources and ideas that support those living with rare diseases.