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 in the U.S. 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!

Spread the Word on Social Media

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 ready-to-use graphics, images, and sample posts sharing key statistics and facts that illustrate the impact rare diseases have on more than 25 million American families and resources for public health professionals, providers, caregivers, advocates, patients, and families.

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

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 Care for People Living with SCD: A model protocol with best practices for caring for people living with sickle cell disease (SCD) and a helpful compendium of tools and resources for providers, patients, and caregivers were developed to accompany the 2017-2021 SCDRCTDP Report to Congress. *Funding for this report was provided by the Health Resources and Services Administration.*

- Reducing Missed Clinic Appointments: People with rare diseases, such as sickle cell disease, experience unique challenges, such as maintaining scheduled appointments. Watch a series of helpful webinars about reducing missed appointments. *This project was*

funded through the Patient-Centered Outcomes Research Institute (PCORI).

NICHQ Initiatives Focused on Rare Diseases

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.

Improving Care for Children with Special Healthcare Needs: NICHQ is leading a learning and action network (LAN) for seven SNAQ teams to support a high-quality system of care in Florida that serves all children and youth with special healthcare needs, regardless of insurance status and location.

Improving Sickle Cell Disease Care - Hemoglobinopathies Coordinating Center: NICHQ, with partner organization Abt Associates, is supporting a Hemoglobinopathies National Coordinating Center (NCC) to help SCD treatment demonstration program grantees — including community and federally qualified health centers — address structural and systemic barriers in their regions and implement evidence-based SCD care.

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.