RARE DISEASE DIVERSITY COALITION

National Organization for Rare Disorders

Inequities in the Rare Disease Community:
The Voices of Diverse Patients and Caregivers
Social Media Toolkit

The Rare Disease Diversity Coalition (RDDC) and the National Organization for Rare Disorders (NORD) successfully completed an essential survey with over 2,800 respondents, aimed at illuminating the barriers that produce critical gaps in rare disease diagnosis, care, and treatment. This comprehensive study has provided vital insights, particularly from underrepresented communities, enhancing our understanding of the unique challenges these patients face.

Our Social Media Toolkit is designed to disseminate key findings from this survey and highlight the impactful collaboration between RDDC and NORD. We encourage you to use this toolkit to help amplify the results, ensuring broader awareness of the gaps and barriers in accessing necessary healthcare for rare disease patients.

Toolkit Table of Contents

Key Messages to Guide Your Social Media Content

Headline

This groundbreaking Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers survey had over 2800 participants.

Outcome of the Survey

This comprehensive study of over 2800 participants has provided vital insights, particularly from underrepresented communities, enhancing our understanding of the unique challenges these individuals face. It illuminates the barriers that produce critical gaps in rare disease diagnosis, care, and treatment.

Track Back to the Mission of RDDC and NORD

- **RDDC's Mission** Rare Disease Diversity Coalition is dedicated to addressing the extraordinary challenges faced by historically underrepresented rare disease patients as encompassed by social determinants of health (SDOH). The Coalition brings together rare disease experts, patients, health care professionals, diversity advocates, and industry leaders to bring about evidence-based solutions that alleviate the disproportionate burden of rare diseases on marginalized populations.

- **NORD's Mission** The mission of NORD is to improve the health and well-being of people with rare diseases by driving advances in care, research and policy.

Basic Facts About Rare Diseases

- There are more than 10,000 rare diseases, of which approximately 95% are still without an FDA-approved treatment or therapy.
- A disease is typically considered rare in the United States if it affects fewer than 200,000 people at any given time.
- Rare diseases are remarkably diverse. They can affect any part of the body and are varied in their complexity. The majority are genetic in origin, while others are the result of infections, allergies, or environmental causes. Some rare diseases are also degenerative and proliferative.

Hashtags

- #rise4rare #rarediseasediversity #NORD #rarediseaseinequities #HealthEquity #RareDiseases #Caregiving

Final Report

- English: Inequities in the Rare Disease Community
- Spanish: Desigualdades en la comunidad que tiene enfermedades raras

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Sample Posts

X formally known as Twitter
Post Copy Suggestions:

*Share the graphic that resonates most with you, accompanied by a message crafted from the provided talking points. Alternatively, you can choose to use any of these statements below as they are.

Option 1
🚨 Groundbreaking Study Alert! 🚨 Over 2,800 voices have illuminated barriers to care for underserved populations with rare diseases. Conducted by @RareDiseaseDiv1 and @NORD.
Inequities in the Rare Disease Community

Option 2
Stand up for the rare disease community and share this groundbreaking study conducted by @RareDiseaseDiv1 and @NORD. Over 2,800 voices illuminate rare disease care barriers.
Inequities in the Rare Disease Community

Option 3
Groundbreaking study for underserved populations with rare diseases. 50% of participants reported they were overwhelmed from managing life, care or caregiving responsibilities. Learn more at rarediseasediversity.org.

Instagram/Facebook/LinkedIn
Instagram - Tag both RDDC and NORD @rarediseasediversitycoalition @nord_rare
Facebook - Tag NORDhttps://www.facebook.com/NationalOrganizationforRareDisorders/
Tag RDDC https://www.facebook.com/profile.php?id=100086789036888
LinkedIn – Tag both RDDC and NORD
https://www.linkedin.com/company/rare-disease-diversity-coalition
https://www.linkedin.com/company/national-organization-for-rare-disorders/

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Option 1
Instagram: 🚨 Groundbreaking Study Alert! 🚨 Explore insights from over 2,800 individuals who have shared their challenges with barriers to care for rare diseases within underserved communities. A staggering 50% of respondents feel overwhelmed by juggling daily life alongside their care or caregiving responsibilities. This study sheds light on the critical barriers that must be addressed to improve health equity. Dive deeper into the findings and join the conversation on how we can make a real change. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

LinkedIn: 🚨 Groundbreaking Study Alert! 🚨 The new data involving more than 2,800 participants highlights significant barriers to care for underserved populations dealing with rare diseases. Alarmingly, half of these individuals report feeling overwhelmed by the demands of managing their health, daily life, or caregiving responsibilities. This study is a crucial step toward understanding and dismantling the obstacles that impede equitable healthcare access. Explore the full report and learn how you can contribute to meaningful change in our community. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

Option 2
Instagram: There is a new groundbreaking study of underserved rare disease patients and caregivers. A distressing 28% of respondents couldn't afford the cost of a medical visit in the past year. This statistic is a stark reminder of the financial barriers that prevent too many people in our communities from accessing necessary medical care. Learn more about the findings. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

LinkedIn: 🚨 New Critical Data from Groundbreaking Study reveals 28% of underserved rare disease patients and caregivers were unable to afford the cost of a medical visit this past year, highlighting a severe barrier to healthcare access. This unacceptable reality affects the health and well-being of underserved populations and underscores the urgent need for systemic change. Learn more about the findings and see how you can be part of the solution. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

Option 3

Instagram: There is a new groundbreaking study of underserved rare disease patients and caregivers. A distressing 20% of people in underrepresented communities delayed or skipped care because they lacked basic needs of food and shelter. This statistic is a stark reminder of the financial barriers that prevent too many people in our communities from accessing necessary medical care. Learn more about the findings. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

LinkedIn: 🚨 New Critical Data from Groundbreaking Study reveals more than 20% of people in underrepresented communities delayed or skipped care because they lacked basic needs of food and shelter, highlighting a severe barrier to healthcare access. This unacceptable reality affects the health and well-being of underserved populations and underscores the urgent need for systemic change. Learn more about the findings and see how you can be part of the solution. #HealthEquity #RareDiseases #Caregiving #rise4rare #rarediseasediversity

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Graphics

See next page. Use the link below to download the digital versions.

[Link To Graphics]

RDDC
RARE DISEASE DIVERSITY COALITION

NORD®
National Organization
for Rare Disorders


GROUNDBREAKING SURVEY

Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers

50% of survey participants reported they were overwhelmed from managing life, care or caregiving responsibilities

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CRITICAL NEW DATA

Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers

33% of survey participants delayed care due to the physical or psychological limitations of their rare disease, making it too difficult to proceed

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CRITICAL NEW DATA

Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers

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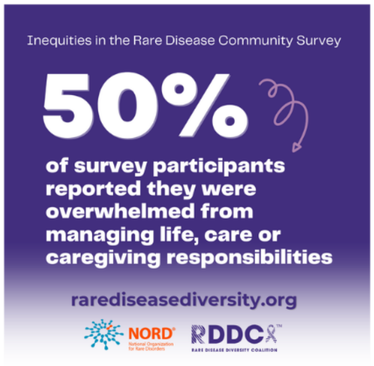
Inequities in the Rare Disease Community Survey

50%

of survey participants reported they were overwhelmed from managing life, care or caregiving responsibilities

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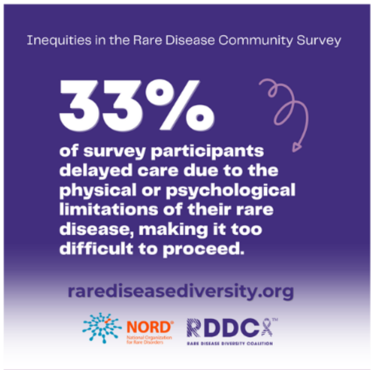
Inequities in the Rare Disease Community Survey

33%

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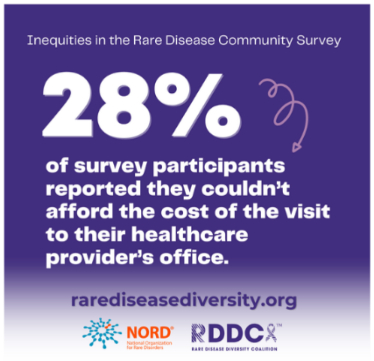
Inequities in the Rare Disease Community Survey

28%

of survey participants reported they couldn't afford the cost of the visit to their healthcare provider's office.

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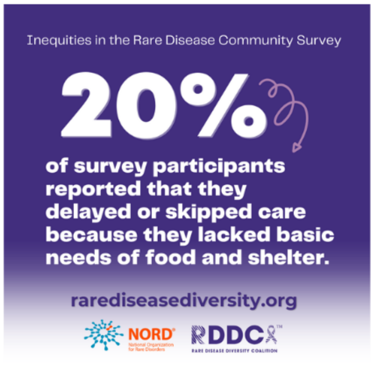
NORD® RDDC


Inequities in the Rare Disease Community Survey

20%

of survey participants reported that they delayed or skipped care because they lacked basic needs of food and shelter.

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