

Myasthenia Gravis (MG) Social Media Toolkit Info

Key Messages to Guide Your Social Media Content

About RDDDC & the Purpose of the Report

The **Rare Disease Diversity Coalition (RDDDC)** elevates the voices of the **#RareWithinRare**, working to eliminate health disparities in rare disease communities by centering patient experiences and addressing the systemic inequities that shape diagnosis, treatment, and health outcomes. In partnership with the Myasthenia Gravis Foundation of America (MGFA), RDDDC proudly presents **How Social Determinants of Health Impact the Myasthenia Gravis Community**, a national, patient-centered report that amplifies lived experiences within the MG community to inform policy change, improve healthcare delivery, and advance equity-driven solutions.

Why This Matters

Myasthenia Gravis (MG) is a rare, unpredictable neuromuscular condition that affects vision, speech, swallowing, breathing, and mobility. Beyond medical symptoms, patients face systemic barriers that delay care, increase financial strain, and impact mental health. This report highlights the lived realities of individuals with MG and the caregivers who support them, ensuring those voices directly shape solutions.

Call to Action

Help elevate the voices of the MG community by reading, sharing, and advocating for them, utilizing content from the MG SDOH Survey Report and Social Media Toolkit. Your support helps drive equitable care, improve insurance protections, and strengthen support systems for patients and caregivers nationwide.

Core Takeaways

This national Social Determinants of Health (SDOH) survey centers the voices of people living with Myasthenia Gravis (MG) and their caregivers across 35 states. Through patient-reported experiences, findings in the report reveal how social, economic, and systemic barriers (such as delayed diagnosis, insurance denials, housing instability, food insecurity, transportation, and mental health access) shape MG outcomes and quality of life.

Top Aims

- **Reduce Diagnostic Delays:** Nearly 40% of MG patients waited 5+ years for a correct diagnosis.
- **Improve Insurance & Treatment Access:** One-third of patients face insurance denials for critical MG treatments.
- **Address Financial Toxicity:** 75% of patients struggled to pay at least one healthcare-related cost.
- **Strengthen Mental Health & Peer Support:** Over half of patients report feeling chronically stressed or isolated.
- **Advance Disability & Employment Protections:** Only 28% of patients can work full-time due to MG.
- **Integrate SDOH Screening into Care:** Housing, food access, and transportation directly impact health outcomes.

RDDDC & Partner Social Media Accounts (Please Tag)

- **LinkedIn:** Rare Disease Diversity Coalition
- **Instagram:** @rare diseasediversity
- **Facebook:** Rare Disease Diversity Coalition
- **X (Twitter):** @rare diseasediv1

Sample Social Media Posts

Instagram, Facebook, X (Twitter)

Sample Post – Long

Living with Myasthenia Gravis (MG) isn't just about managing symptoms, it's about navigating delayed diagnosis, insurance denials, rising healthcare costs, and access to basic needs like food, transportation, and mental health care.

Our national MG Social Determinants of Health Survey reveals:

- 75% struggle to afford healthcare.
- 39% waited 5+ years for diagnosis.
- Over half report chronic stress & isolation.
- 26% delayed care due to transportation barriers.

Read the full report and join us in advocating for equity-driven solutions.

[Insert Link to Report]

#MyastheniaGravis #RareDisease #HealthEquity #PatientVoices #BWHI #RareWithinRare #RDDC #MGFA

Sample Post – Short

- Nearly 4 in 10 MG patients waited over 5 years for a correct diagnosis. Delayed care costs lives.
[Insert Link to Report]
#MyastheniaGravis #RareDisease #PatientEquity #RDDC #MGFA
- 75% of MG patients struggle to afford at least one healthcare cost. Financial toxicity is a public health crisis.
[Insert Link to Report]
#HealthcareCosts #HealthEquity #MGCommunity #RDDC #MGFA
- More than half of MG patients report feeling stressed or isolated. Mental health support must be part of MG care.
[Insert Link to Report]
#MentalHealthMatters #RareDiseaseSupport #RDDC #MGFA
- 26% of MG patients delayed care due to transportation barriers. Access should never depend on location.
[Insert Link to Report]
#AccessToCare #TransportationEquity #MyastheniaGravis #RDDC #MGFA
- Only 28% of MG patients can work full-time due to symptoms. Employment protections matter.
[Insert Link to Report]
#DisabilityRights #WorkplaceEquity #MGAdvocacy #RDDC #MGFA

LinkedIn Sample Posts

Long

The Rare Disease Diversity Coalition, in partnership with the Myasthenia Gravis Foundation of America, released the first national Social Determinants of Health survey for the MG community. The data reveals how delayed diagnosis, insurance denials, housing instability, food insecurity, and financial strain directly impact health outcomes.

These findings provide a patient-driven roadmap for clinicians, policymakers, and advocates to advance equity in MG care.

Read the full report: [Insert Link to Report]

#RareDisease #HealthEquity #PatientCenteredCare #MGCommunity #PolicyChange #RDDC #MGFA

Short

- 47% of MG patients required 3+ physicians to get the right diagnosis. Earlier detection saves lives.
[Insert Link to Report]
#DiagnosticEquity #RareDisease #RDDC #MGFA
- One-third of MG patients report their insurance does not cover essential treatments. Coverage ≠ Access.
[Insert Link to Report]
#InsuranceReform #HealthEquity #RDDC #MGFA
- Caregivers of MG patients report high stress and limited formal support. They need resources too.
[Insert Link to Report]
#CaregiverSupport #RareDiseaseAdvocacy #RDDC #MGFA

MG Social Media Graphics

Please pair graphics with the post(s) that best reflects your voice as an advocate or ally.

[RDDC Social Media Graphics Folder](#)