# The Social Work Role in Healthcare to Support Patients with Myasthenia Gravis

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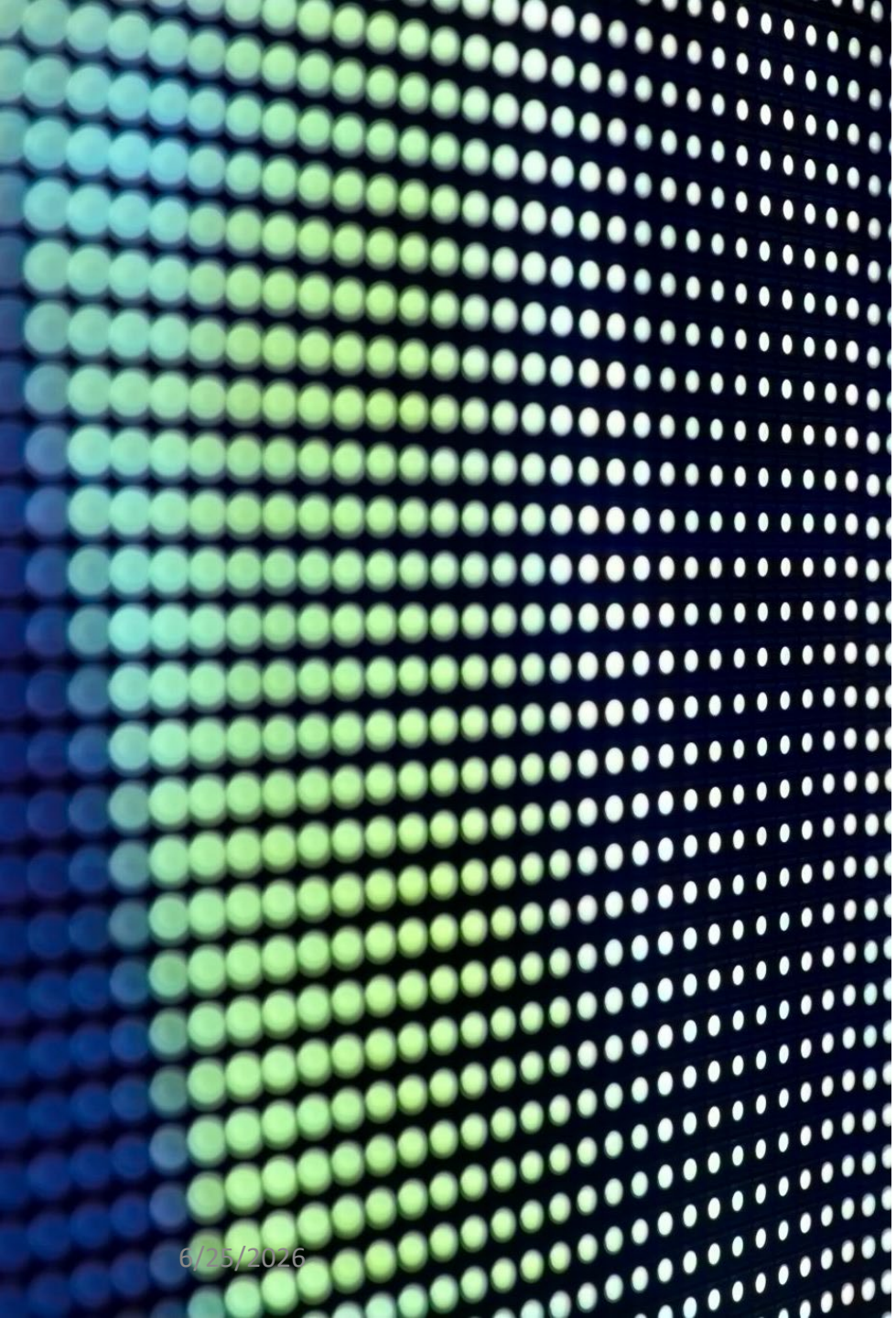


# Objectives

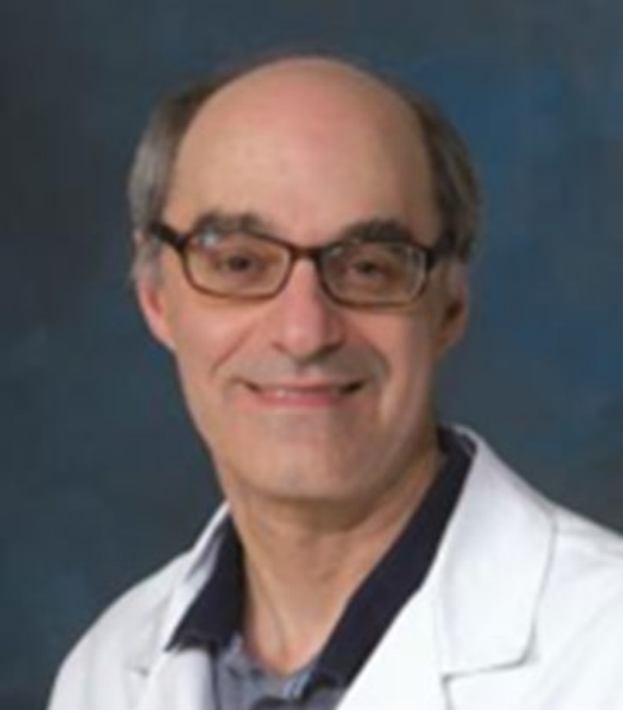
- Introduction to MetroHealth & Our Neuromuscular Clinics, Emphasizing the Importance of Interprofessional Care and Collaboration
- Talk About the Importance of the Social Work Role in Understanding Patient's Medical & Psychosocial Concerns
- Discuss How Social Determinants of Health Impact the Myasthenia Gravis Community, Including Social Work Interventions that Can Help Promote Quality of Life


# The MetroHealth System, Cleveland, Ohio

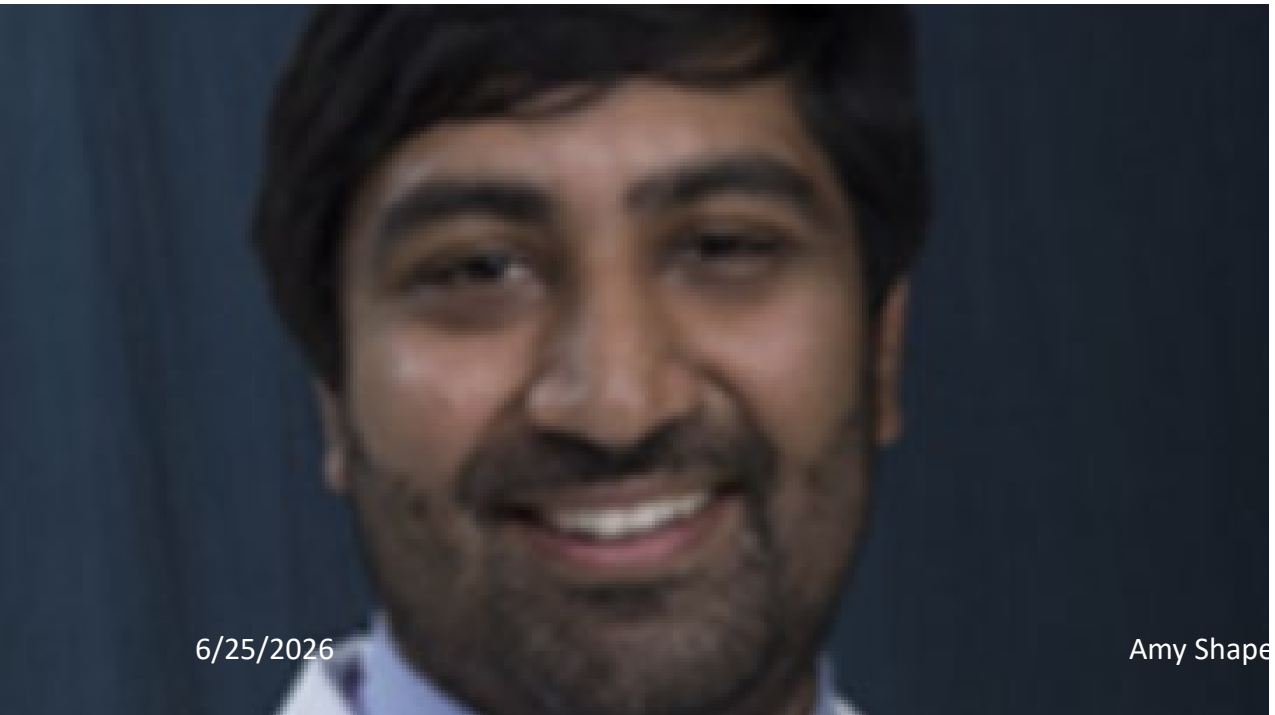
- Founded in 1837
- Cuyahoga County's Safety Net Health System
  - Serves more than 300,000 patients annually
  - Two-thirds are uninsured or covered by Medicare or Medicaid
- The MetroHealth Glick Center, a new 11 floor hospital opened October 2022
- New Outpatient Health Center Opening July 2026

# MetroHealth Information

- Academic medical center committed to teaching and research; each of our active staff physicians hold a faculty appointment at Case Western Reserve University School of Medicine.
- MetroHealth earned Magnet status, placing it in the top six percent of all hospitals nationwide for nursing excellence.
- Social Work Department created in 1924 & is the second oldest in the nation
- First safety net hospital in 1999 to install EPIC
- Affiliation with the Muscular Dystrophy Association since 1962







# MetroHealth Neuromuscular Team Neurologists

- Dr. Marc Winkelman
- Dr. Andre Prochoroff
- Dr. Daniel Benson
- Dr. Hermani Ticku
- Dr. Mankaran Sawhney

# Other Potential Neuromuscular Team Members for the Management of Myasthenia Gravis

- Speech therapy
- Respiratory therapy
- Physical Therapy
- Occupational Therapy
- Pharmacy
- Social Work

# Medical Care Settings for Myasthenia Gravis

## Outpatient

- Most patients with Myasthenia Gravis are treated on an outpatient basis.
- Initial management often starts with symptomatic therapy (pyridostigmine) and may progress to immunosuppressive drugs like corticosteroids or nonsteroidal agents.
- Outpatient visits allow for ongoing assessment of symptoms, medication side effects, and disease progression, enabling timely adjustments to therapy

## Inpatient

- Hospitalization for myasthenia gravis is primarily indicated for patients at risk of respiratory compromise, severe generalized weakness, or rapidly progressive symptoms requiring close monitoring and advanced therapies.

## Telehealth/ eHealth at Home

- Addresses physician scarcity by enhancing access to populations who may otherwise experience barriers due to geographical or physical disability
- Can be performed anywhere & has the potential to minimize overhead resources
- Can help patients stay connected to their established physician or care team by preserving continuity of care, enabling team-based coordination and improving access.

# The Importance of Coordinated Interprofessional Care & Collaboration

Consensus guidelines increasingly report interprofessional care as the standard for NMD's, particularly for adult & pediatric populations.

Improved resource utilization

Improved patient satisfaction

Firmly established as an important component within education & healthcare

Emerging evidence that when interprofessional healthcare teams practice collaboratively it can enhance the delivery of person-centered care and lead improved patient & health system outcomes.

# What is an Interprofessional Team?

DEFINED AS A GROUP OF DIFFERENT PROFESSIONALS AND HEALTH WORKERS WHO SHARE A COMMON IDENTITY AND WORK TOGETHER IN AN INTEGRATED AND INTERDEPENDENT MANNER TO SOLVE COMPLEX CARE PROBLEMS AND PROVIDE HEALTH SERVICES.

IT INVOLVES HAVING A COMMON OBJECTIVE, DIFFERENTIAL PROFESSIONAL CONTRIBUTIONS, AND A SYSTEM OF COMMUNICATION AMONG TEAM MEMBERS.

HTTPS://PMC.NCBI.NLM.NIH.GOV/ARTICLES/PMC8873279/

# MetroHealth Neuromuscular Clinics and the Addition of Social Work

- Designated outpatient social worker assigned in 2017
- Pediatric multidisciplinary clinic (2nd & 4th Tuesday), ALS/MDA interdisciplinary clinic (1st Thursday)& adult clinic (Thursday)
- Medical Social Work Model
- Social work services are offered to ALL patients (> 300)

# Healthcare Social Work

A Health care Social Worker is a specialized professional in the social work field who addresses complex emotional, social, and practical aspects of a patient's healthcare journey.

The 10-year national workforce is projected to grow 3.07%, but Healthcare Social Workers are expected to see a growth of 7.71%, which is more than the national average according to https://datausa.io/profile/soc/healthcare-social-workers

Nearly all social work careers in healthcare require a Master's Degree in Social Work with a clinical focus.

Ida Cannon was responsible for developing the first social work department in a hospital (in the U.S.) at Massachusetts General Hospital. She became the Chief of Social Services in 1914.

# Ida Cannon

- In a 1930 address she described the role as: “The medical Social Service movement recognizes that there should be within the hospital…. Someone definitely assigned to represent the patient’s point of view….and to work out with the physician, an adaptation of the medical treatment in the light of the patient’s social condition”.
- https://socialwelfare.library.vcu.edu/people/cannon-ida-maude/

# Margaret Wagner, Director of MetroHealth Social Service Department 1924

- “It was a serious responsibility for the introduction of social service as evidence of a growing concept that one treated a man, and not a disease. It was an acknowledgment that there could be a relationship between illness and emotional and psychological factors as the medical social worker joined the professional team to contribute to diagnosis and treatment, to teaching and research. Social Service added another dimension to the practice of medicine”.


# Social Work Services at MetroHealth

The following services can be requested by a patient or by a family member, healthcare provider or community agency working with a patient:

- **Discharge Planning**: Coordinating discharge to appropriate level of care and helping to ease the transition to a new environment.
- **Crisis Intervention**: Assisting patient and family in managing immediate problem, coping and making decisions while dealing with a traumatic event.
- **Psychosocial Assessment**: Obtaining information regarding patient's development, history and functional capacity within the community to identify factors that could impact patient's recovery or compliance with medical plan.

# Social Work Services at MetroHealth (continued)

**Short Term Counseling**: Addressing issues such as grief, caregiver support, domestic violence, sexual assault, pregnancy, substance abuse, mental health and behavior problems and referring to appropriate agency for follow up.

**Referral to Community Resources**: Linking patient to community resources based on identification of need.

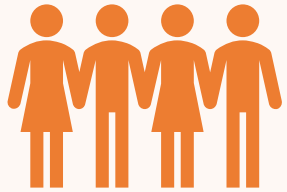
**Medicaid and Disability**: Providing patients/families with what they need to access services.

**Medication Assistance**: Assisting patients in determining the most economical means of obtaining medications.

**Consultation**: Providing healthcare team with psychosocial information and recommendations to assist with medical management and planning.

**Advanced Directives/Guardianship**: Provide assistance in completing the Health Care Power of Attorney process and living wills, as well as information and guidance regarding guardianship, custody issues and adoption.

# Recent Social Determinants of Health or SDOH Survey Results for MG Patients



**Social Determinants of Health are factors that influence health outcomes including:**

Economic stability

Education access

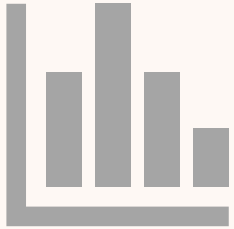
Healthcare access

Neighborhood & environment

Gender

Race

Food Access Security



**Important Key Findings in Rare Disease Diversity Coalition (RDDC) MG SDOH Survey**

National Survey completed February 2026
https://rarediseasediversity.org/hubfs/RDDC/pdf/RDDC-MG-SDOH-Report-2.pdf

# The Diagnostic Journey for MG Patients Remains Long & Inequitable

**~ Half of MG patients reported significant diagnostic delays.**

**47% of respondents received an exact diagnosis either less than a year or within 1-2 years from symptom onset.**

**39% waited five years or more for a correct diagnosis.**

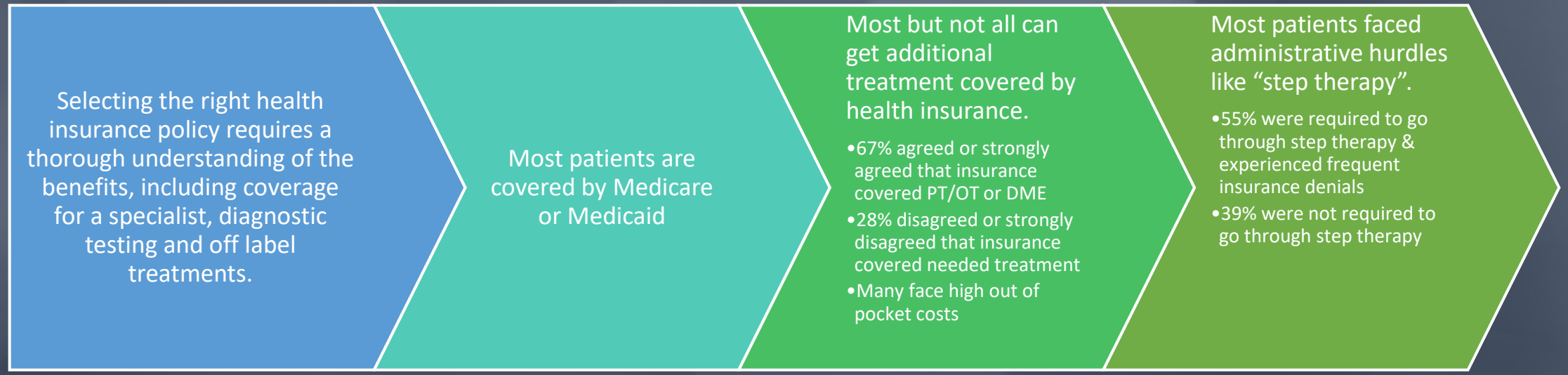
**Many experienced multiple misdiagnoses (which is the norm).**

41% received 1-2 incorrect diagnoses

33% received 3-4 incorrect diagnoses before getting the right one

**The complexity & rarity of MG contributes to barriers, underscoring the need for improved clinician education & care coordination.**

# Insurance Coverage Alone has NOT Eliminated Barriers to Care



# Lack of Support for Social Determinants of Health Drives Poor Outcomes

Challenges related to housing instability; food insecurity & lack of reliable transportation negatively affects health outcomes.

~ Half of patients in the survey rented their homes, 37% worry about running out of food, & 26% experienced care delays due to transportation barriers.

Research has found that housing status has the greatest impact on health outcomes over other demographic factors, including drug or alcohol use, or mental health status.

# Housing & Neighborhood Results

37% of patients owned their home

47% rented

10% lived with family or friends

64% always felt safe in their home

32% felt safe sometimes

3% said they do not feel safe

58% reported having at least one problem with housing

# Patient Provider Communication

71% of patients think that their doctor always or usually explains things in a way that they can easily understand

25% of patients find that their doctor only sometimes explains things in a way that they understand

73% are always or usually comfortable speaking with their doctor

24% of patients are sometimes comfortable speaking with their doctor

48% were asked to take part in clinical trials & 40% participated

Using empathy & cultural competence during treatment and when educating patients about MG can improve patient outcomes by increasing patient engagement and adherence to treatment plans.

# Non-Medical Barriers to Care

CAN BE FINANCIAL BURDENS, TRANSPORTATION, AVAILABILITY OF SPECIALISTS, SYSTEMIC DISCRIMINATION, AND UNCONSCIOUS PROVIDER BIAS.

39% OF PATIENTS WITH RARE DISEASE HAD TO TRAVEL MORE THAN 60 MINUTES FOR CARE.

35% GET MG CARE WITHIN 20 MILES FROM HOME.

51% GET MG CARE WITHIN 20-40 MILES FROM HOME.

LACK OF TRANSPORTATION IS THE MOST SIGNIFICANT BARRIER TO CARE.

COST REMAINS A BARRIER TO CARE.

LACK OF AVAILABLE APPOINTMENTS LED TO DELAYED CARE.

# Financial Strain & Employment Challenges are Pervasive

- 28% of respondents were able to work full time.
- 36% were employed part time.
- 17% were unable to work due to poor health.
- 75% of patients reported financial difficulty paying for at least one healthcare cost, including medications, equipment or medical bills.
- 43% received financial or disability benefits.
- Symptom and disease management make it difficult for MG patients to work full time without adequate workplace accommodations.

# Managing Healthcare Costs

A NIH study reports that healthcare costs for people with a rare disease are three to five times greater than the costs for people without a disease.

75% reported difficulty paying for one of the following:

- 43% had difficulty paying for medical bills
- 30% had difficulty paying for prescription medicine
- 18% had trouble paying for medical equipment
- 16% had difficulty paying dental bills
- 8% had difficulty paying for nursing care

# Access to Healthy Food

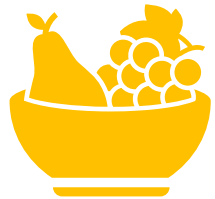
**Studies have shown that access to healthy food and nutrition can improve health outcomes and lower healthcare costs.**

Healthy foods are more expensive and less accessible in some low-income communities

**Most MG patients worry about running out of food before they can afford to buy more.**

32% either are always or usually worried

28% were sometimes worried



**Having MG makes it harder to buy and prepare healthy meals.**

61% reported it is always or typically easy to find healthy foods locally

27% reported it is sometimes easy to find healthy foods locally

# Mental Health

Rare disease patients face unique mental health challenges stemming from the widely misunderstood nature of their rare condition and journey to diagnosis.

Added stress comes from navigating health insurance coverage of treatments and limited access to specialists, in addition to difficulties associated with lack of support services to live independently.

~ Half of all patients reported often feeling stressed or lonely.

63% of patients reported accessing mental health services when needed.

Most patients & caregivers rely on MG support groups.

# Rare Disease Caregiving

- Caregivers of individuals living with a rare disease are usually family members.
- The inherent uncertainty surrounding rare disease is stressful for caregivers.
- Studies show that the poor mental & physical health of caregivers has a direct impact on the person they are caring for.
- Patients & caregivers consistently emphasize the importance of peer connection in addressing their physical & mental well-being.
- 62% usually or always get the help they need.
- 53% of caregivers report feeling always or usually stressed or overwhelmed.
- 40% of caregivers report feeing always or usually lonely or isolated
- Most caregivers have a college education

# Recommendations from MG Community Regarding MG SDOH Study

1

Expand mental health and support group access immediately upon diagnosis.

2

Improve education for healthcare providers and emergency clinicians on MG diagnosis and management.

3

Advocate for greater recognition of MG as a qualifying condition for disability benefits and workplace accommodations.

4

Develop a national MG specialist network and improve insurance coverage for MG-specific treatments and supportive services.

# The Study of Social Participation and its Influences on Young and Middle-Aged Patients with MG

- Social participation levels among young & middle-aged MG patients are suboptimal.
- Attention should be directed towards patient's engagement in self care, general activities, and independent social life relationships.
- Special focus should be given to female patients, those from rural areas, patients who need daily care, and those with weak daily activity abilities, have longer disease durations, more severe depressive symptoms, and poorer family functioning.
- Health education, psychological support, and active family involvement may improve social participation levels.
- https://pmc.ncbi.nlm.nih.gov/articles/PMC12558821/

# Association of Race & Social Determinants of Health with Exacerbations in Generalized Myasthenia Gravis Article

- Potential racial disparities exist in the occurrence of MG exacerbations.
- Risk of MG exacerbations was significantly higher among Black versus White patients.
- A lower risk for MG exacerbations was observed among Asian patients compared with White patients.
- Primary care physicians are less likely to refer Black patients than White to a specialist & Black patients are ~ 30% less likely than Whites to see a neurologist.
- Black individuals are more likely to be cared for in an emergency department, have more hospital stays and have higher inpatient expenditures compared to their White counterparts.
- https://onlinelibrary.wiley.com/doi/full/10.1002/mus.7022?msockid=07c61ed34fdb620a154e08e14ebd6394

# Factors Associated with Quality of Life of People with MG (2018 article)

Gender was not a significant factor in explaining QOL

Age was a significant factor for the patient's physical QOL; older persons with MG experienced lower physical QOL.

Participants seemed to experience higher QOL when their career had not changed due to their illness.

The more depressed the patients were, the lower physical & mental QOL reported

Those perceiving less support from medical professionals experienced higher QOL

- Possibility that people who are functioning relatively well do not communicate with their medical professionals in depth.

# Factors Associated with Quality of Life of People with MG (continued), Including Recommendations

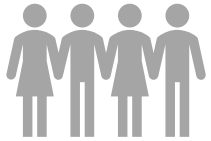
- Loneliness was not found significant in explaining the patient's QOL.
  - Possibility that the perceived lack of social support is not necessarily experienced as loneliness.
- Career change and depression were the most significant predictors of MG patients' QOL.
- Once diagnosed with a medical condition that does not have a quick & easy solution, people could become more vulnerable to multiple types of manifestation of lower mental QOL, including depression, low self-esteem, and social withdrawal.
- Systemic support for people with chronic illness can be effective when implemented in the work-place.
- Providing programs that include career construction counseling with connections to suitable alternative workplaces can be effective.
- Psychotherapy or group therapy may encourage patients to cope with their mental stress and strengthen self esteem.
- https://pmc.ncbi.nlm.nih.gov/articles/PMC6226107/

# Effectiveness of Social Work in Supporting Myasthenia Gravis Patients

**Improving social participation**

Address barriers linked to lower participation including unemployment, rural residence, weak daily activity ability, depression, poor family functioning and long disease duration

Facilitate vocational support, family education & community reintegration



**Enhancing social support**

Help connect patients with peer support groups or caregiver training, and link to community resources

**Addressing Social Determinants of Health/ SDOH**

Advocate for accessible care, connect patients with financial aid and all available community support programs.

# Effectiveness of Social Work in Supporting MG Patients (Continued)

## Psychosocial & Emotional benefits

- Social work interventions can reduce depression & anxiety, improve coping strategies and strengthen family functioning.
- Fostering resilience to help patients regain social roles to improve long term health outcomes.

## Practical Social Work Strategies

- Assessing barriers to care- identify social, emotional & practical barriers.
- Support Network Development- facilitate connections with peers, caregivers & community resources.
- Advocacy- push for policy changes or program expansion to support the underserved.
- Education- provide information on disease management and legal rights.
- Crisis Intervention- offer immediate support during periods of acute symptom exacerbation.


Thank you!

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