

# Treatment Decisions Pulse Poll Report

## Navigating Treatment Options for Amyotrophic Lateral Sclerosis (ALS) & Myasthenia Gravis (MG)

We surveyed **694 patients** (268 with ALS, 426 with MG) to uncover what's driving or delaying their treatment decisions.

### Why 1 in 5 ALS Patients Still Aren't Taking FDA-Approved Drugs—Do You Know the Reason?



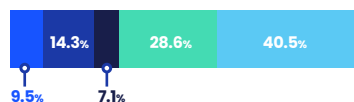
% of non-treating patients despite FDA-approved options

**18.4%**  
ALS patients

**10.7%**  
MG patients



#### ALS



**9.5%** My symptoms are not severe enough.

**14.3%** Insurance will not cover it.

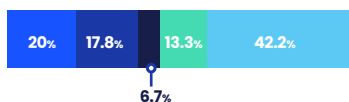
**7.1%** My physician does not recommend it.

**28.6%** I am concerned about side effects.

**40.5%** Others:

- Burden of Side Effects and Lack of Symptom Relief.
- Preference for Quality of Life Over Marginal Extension.
- Access Barriers, Clinical Ambiguity, and Perceived Ineffectiveness.

#### MG



**20%** My symptoms are not severe enough.

**17.8%** Insurance will not cover it.

**6.7%** My physician does not recommend it.

**13.3%** I am concerned about side effects.

**42.2%** Others:

- Limited Access and Barriers to Appropriate Treatment.
- Off-Label, Experimental, or Tailored Approaches.
- Mixed Treatment Experience and Disease Stability.

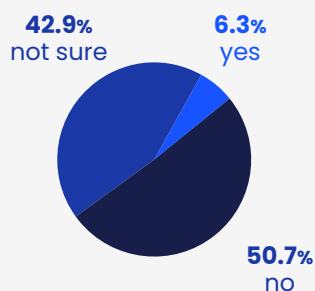
#### REASONS

ALS/MG Patients are skipping FDA-approved treatments. Here's what they're actually feeling.

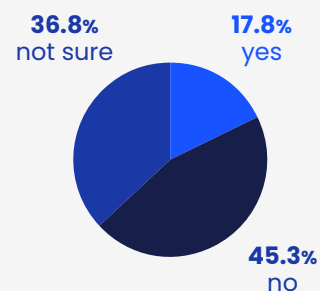
## SWITCHING MEDICATIONS

# Patient openness to switching current medications

ALS



MG



**MG Patients want better options—and they're ready to switch. Are you listening?**

## Side Effects or Something Deeper?

**Why ALS and MG Patients Truly Switch Medications.**



**15.3%** My current treatment is not effective.

**3.7%** My insurance coverage has changed and no longer covers it.

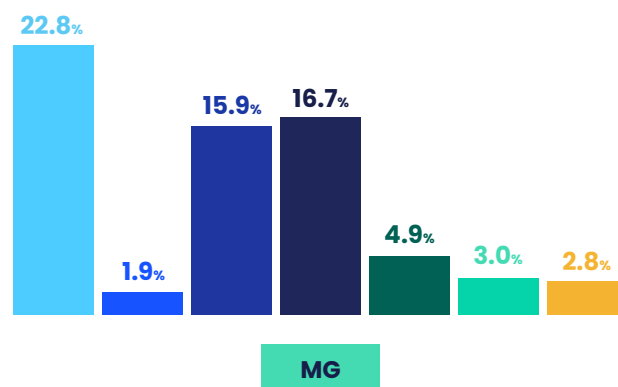
**22.0%** A new drug is approved or expected to be approved.

**11.9%** My physician recommended it.

**6.3%** The side effects are intolerable.

**2.2%** The dosing is inconvenient.

**1.9%** The administration method is inconvenient or not feasible for me.



**22.8%** My current treatment is not effective.

**1.9%** My insurance coverage has changed and no longer covers it.

**15.9%** A new drug is approved or expected to be approved.

**16.7%** My physician recommended it.

**4.9%** The side effects are intolerable.

**3.0%** The dosing is inconvenient.

**2.8%** The administration method is inconvenient or not feasible for me.



# When ALS/MG patients need answers, who do they trust first?

Where patients seek information about their condition and treatment

## "Condition-specific websites"

85.3%

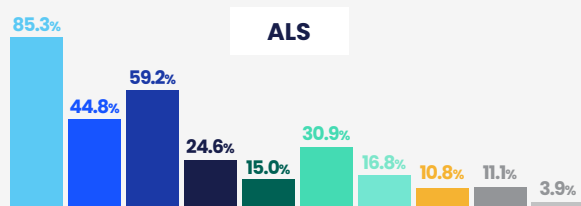
ALS patients

www.alsnewstoday.com

87.6%

MG patients

www.myastheniagravisnews.com



85.3% Condition-specific websites (alsnewstoday.com)

44.8% General health information sites (e.g., Healthline, WebMD, Everyday Health)

59.2% Patient communities (alsnewstoday.com)

24.6% Medical journals (e.g., Lancet, JAMA)

15.0% Pharmaceutical/drug brand sites

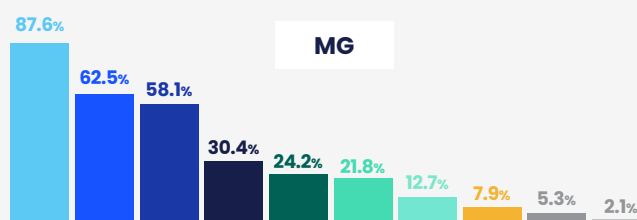
30.9% Social media (e.g., Facebook, X, Instagram)

16.8% Offline media (e.g., magazines, newspapers)

10.8% Other

11.1% Social media influencers

3.9% AI (e.g., ChatGPT, Gemini)



87.6% Condition-specific websites (myastheniagravisnews.com)

62.5% General health information sites (e.g., Healthline, WebMD, Everyday Health)

58.1% Patient communities (myastheniagravisnews.com)

30.4% Medical journals (e.g., Lancet, JAMA)

24.2% Pharmaceutical/drug brand sites

21.8% Social media (e.g., Facebook, X, Instagram)

12.7% Offline media (e.g., magazines, newspapers)

7.9% Other

5.3% Social media influencers

2.1% AI (e.g., ChatGPT, Gemini)

## Who Really Shapes Patient Decisions?

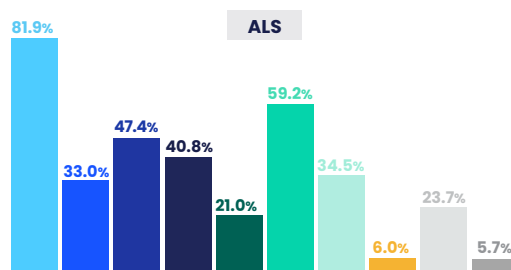
### The Influencers You Can't Ignore

People and sources influencing patients' treatment decisions.

#1 Healthcare professionals (e.g., doctor, nurses)

#2 Other diagnosed patients

#3 Personal research and experience



81.9% Healthcare professionals (e.g., doctor, nurses)

33.0% Support groups

47.4% Other diagnosed patients

40.8% Caregivers and family members

21.0% Media news sources

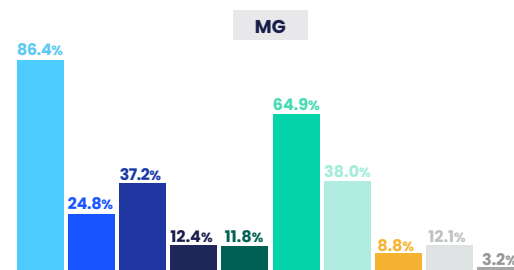
59.2% Personal research and experience

34.5% Insurance coverage and cost

6.0% Pharmaceutical advertisements

23.7% Complementary and alternative medical practitioners (e.g., acupuncturists, masseuses, wellness coaches, homeopaths)

5.7% Social media influencers



86.4% Healthcare professionals (e.g., doctor, nurses)

24.8% Support groups

37.2% Other diagnosed patients

12.4% Caregivers and family members

11.8% Media news sources

64.9% Personal research and experience

38.0% Insurance coverage and cost

8.8% Pharmaceutical advertisements

12.1% Complementary and alternative medical practitioners (e.g., acupuncturists, masseuses, wellness coaches, homeopaths)

3.2% Social media influencers

## About Bionews

Bionews is the leading rare disease news and community network, built on over a decade of serving and supporting patients and caregivers.

Across 50+ condition-specific communities, we've earned deep trust by delivering credible news, research, lived insights and peer connection —making Bionews the most trusted voice in rare disease today.

### Rare Reach

Bionews has spent over a decade building the largest online network of rare disease communities, reaching an astounding average of **72% of the domestic diagnosed patient population\***. Our scale within niche rare disease audiences offers pharmaceutical partners unparalleled access to engaged, highly targeted patients.

**50+**

Rare Disease  
Communities

**72%**

Avg. U.S. Rare Disease  
Patient Population Reach\*

**1+ Million**

Rare Disease Patients  
Reached Per Month\*

\*Avg. monthly domestic  
reach across top 20 rare  
disease communities

### Rare Audience Quality

Bionews is the **#1 online source** for rare disease news and community. Our condition-specific communities are trusted destinations for patients and caregivers who are actively researching their diagnosis, exploring treatment options, and seeking peer support.

This intent-driven engagement creates a uniquely qualified audience—deeply informed, highly motivated, and ready to act. For pharmaceutical partners, this means your message reaches patients at precisely the moment they're making decisions that matter.

**#1**

Rare Disease News Source  
for Patients & Caregivers

**87%**

Audience is Diagnosed  
Patient or Caregiver

**47x**

Avg. Targeting  
Multiple\*

\*Source: Crossix 2024

### Rare Engagement

What sets Bionews apart is the authenticity and trust we've earned within our **50+ rare disease communities** over the past decade. Our communities are safe, condition-specific spaces where patients come to seek credible clinical information and make informed treatment decisions. This high-intent, research-driven mindset fuels the strongest engagement in the industry—and delivers real impact for our pharmaceutical partners.

**4:32**

Min Avg. Session Time

**0.22%**

Avg. Ad CTR

**40%**

Avg. Email Open Rate

## About the Report

Our latest Pulse Poll Report reveals candid, real-world insights from rare disease patients across two of our most engaged rare disease communities.

To gain insights like these for any of our other 50+ rare disease communities contact Ethan Ash, EVP of Business Development, at [ethan.ash@bionews.com](mailto:ethan.ash@bionews.com).