health union

WHITE PAPER

Living Rare

Universal Truths of Patient Attitude, Action, and Advocacy in Rare Disease

HEALTH UNION INSIGHTS | 2026 RARE DISEASE MARKET INTELLIGENCE

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1,404
rare disease patients and caregivers surveyed across the U.S.

51%
had to consult multiple healthcare providers before a diagnosis

58%
have felt stigmatized or judged because of their condition

Health Union Insights Team

Based on Rare Disease In America 2026 survey data

Introduction: Seeing the Patient Behind the Rarity

In pharmaceutical marketing, rare disease strategy is frequently anchored in molecular science, specialized diagnostic codes, and niche patient populations. While medical differentiation is essential, focusing solely on biological mechanisms risks overlooking a crucial reality:

Across thousands of distinct rare conditions, patients share a remarkably unified human experience.

Data from the Health Union 2026 Rare Disease in America Study (n=1,404 rare disease patients and caregivers) reveals that despite varying clinical presentations, rare patients navigate remarkably similar emotional, logistical, and social hurdles. From multi-year diagnostic odysseys to pervasive social misunderstanding, the rare journey is defined less by diagnostic isolation and more by universal patterns of coping, self-advocacy, and proactive search for answers.

For healthcare marketers and brand stewards, understanding these shared behavioral truths is essential. Connecting with rare patients requires moving past generic empathy to address the structural and emotional friction points that shape their daily lives.

ABOUT THE STUDY

1,404	1,325	79	60+
U.S. adults surveyed	patients	caregivers	rare conditions

01 The Diagnostic Odyssey and Healthcare Friction

35%	16%	40%	37%
waited more than a year from first seeking care to a diagnosis	waited more than five years	had symptoms initially dismissed by healthcare providers	were first misdiagnosed with another condition

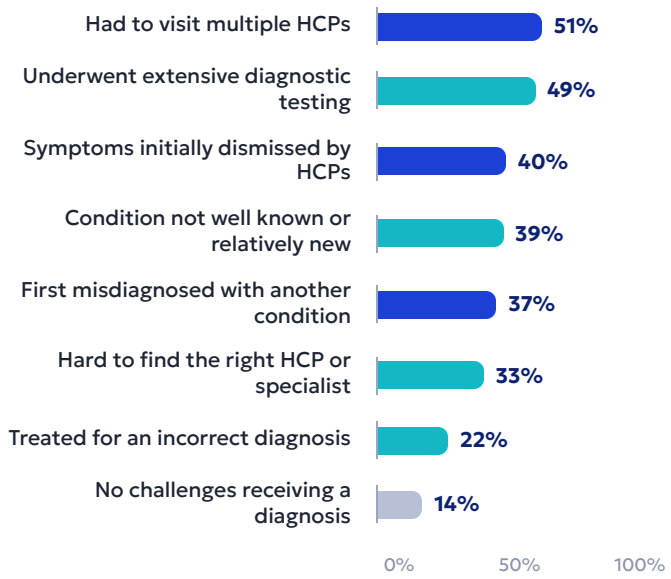
The Multi-Doctor Reality

The path to an accurate rare diagnosis remains an uphill battle. According to our research, **35% of patients waited more than a year** from the time they first sought care to receive an accurate diagnosis, and **51% had to consult multiple healthcare providers** before finding answers.

This extended search creates deep-seated skepticism toward the traditional medical establishment. Many patients report feeling dismissed, misdiagnosed, or told their symptoms were psychosomatic before securing a specialty referral. Consequently, by the time a rare disease patient reaches a brand touchpoint, they are rarely naive consumers; they are seasoned navigators who have learned to question medical authority and demand concrete proof.

Challenges Experienced on the Way to a Diagnosis

Multiple responses allowed. Only 14% reached a diagnosis without any challenges.



Base: Total sample (n=1,404)

REAL PATIENT VOICES: DIAGNOSTIC ISOLATION

> **Mostly being gaslit by physicians who gave the wrong diagnosis because they lack the training to know what they were looking for.**
>
> CUSHING'S SYNDROME PATIENT

> **Largely it is due to lack of understanding. Most providers have only heard of it in a textbook.**
>
> MYASTHENIA GRAVIS PATIENT

MARKETER TAKEAWAY

Build Validation Into Brand Messaging

Brand communications must acknowledge this arduous diagnostic history. Marketing materials should validate the patient's lived experience immediately rather than assuming a smooth clinical journey. Educational content that helps patients articulate complex symptoms to their physicians directly addresses their greatest early-stage pain point.

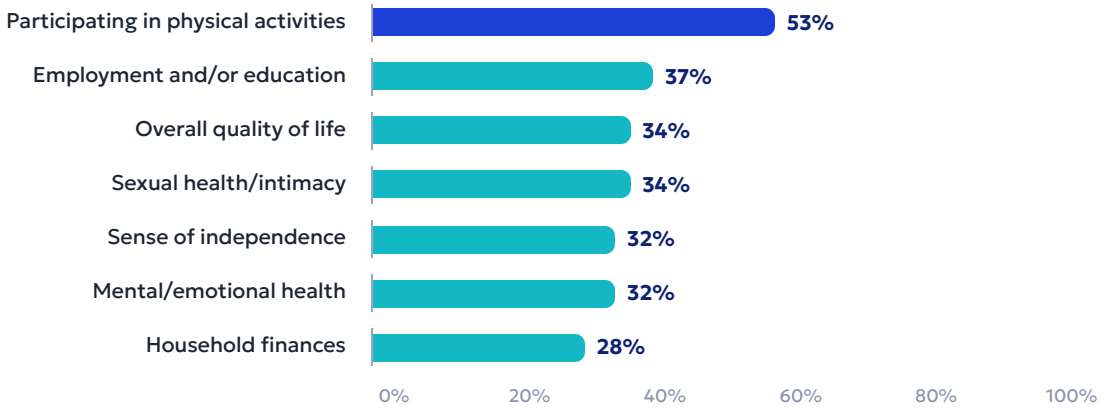
02 The Daily Impact: Loss, Adaptation, and Stigma

Living with Physical Limitations and Invisible Stigma

A rare diagnosis reshapes a patient's entire lifestyle. Over half of respondents (**53%**) report a significant negative impact on their ability to participate in physical activities, and **70%** rely on at least one assistive device to manage daily tasks.

Where Rare Disease Takes the Biggest Toll

% rating a significant negative impact (6 to 7 on a 7-point scale).



Base: Total sample (n=1,404); sexual health asked of patients only (n=1,325)

Beyond physical constraints, rare disease carries a heavy social burden. A striking **58%** of patients have felt stigmatized or judged due to their condition. Paradoxically, this judgment stems most frequently from those closest to them: family members (**31%**) and friends (**25%**). Because many rare conditions fluctuate in severity or present without obvious external signs, patients are frequently accused of exaggerating fatigue or making excuses.

Only 19% of patients feel that others truly understand what it is like to live with their rare condition, and only 22% believe their condition does not prevent them from enjoying life.

REAL PATIENT VOICES: EMOTIONAL AND SOCIAL STRAIN

> **Isolation. I look healthy but body says another thing. Tired of explaining to people why my body and mind are exhausted at the end of the day and I just want to lay down.**
>
> PRIMARY BILIARY CHOLANGITIS PATIENT

> **People either think we are living a death sentence and talk to you like you are a four year old, or they dismiss what we go through like it is all made up.**
>
> ACHALASIA PATIENT

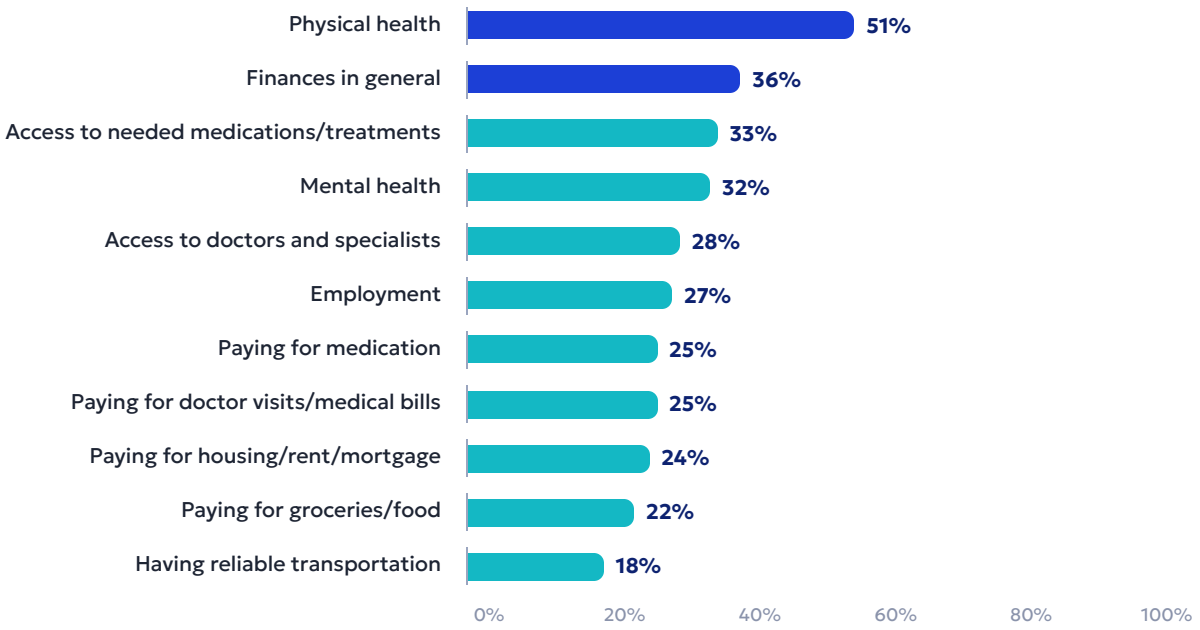
03 Financial and Top-of-Mind Worries

Dual Pressures: Physical Health and Financial Strain

When assessing daily anxieties, physical health tops the list, with **51%** worrying a lot about their ongoing physical well-being. However, financial anxiety is almost as prominent: **36%** worry a lot about their finances in general, and **33%** worry about keeping access to the medications and treatments they need.

What Rare Patients Worry About Most

% who worry a lot (6 to 7 on a 7-point scale).



Base: Patients only (n=1,325)

Rare therapies often carry high cost-sharing responsibilities, specialized administration requirements, or travel burdens to reach regional centers. Paying for medication (**25%**) and medical bills (**25%**) weigh on patients alongside concerns over mental health (**32%**).

MARKETER TAKEAWAY

Holistically Support the Patient Lifestyle

Effective rare disease management requires supporting the whole person, not just prescribing a treatment. Patient support programs must offer robust financial navigation, clear co-pay assistance, and lifestyle resources that preserve patient independence and dignity.

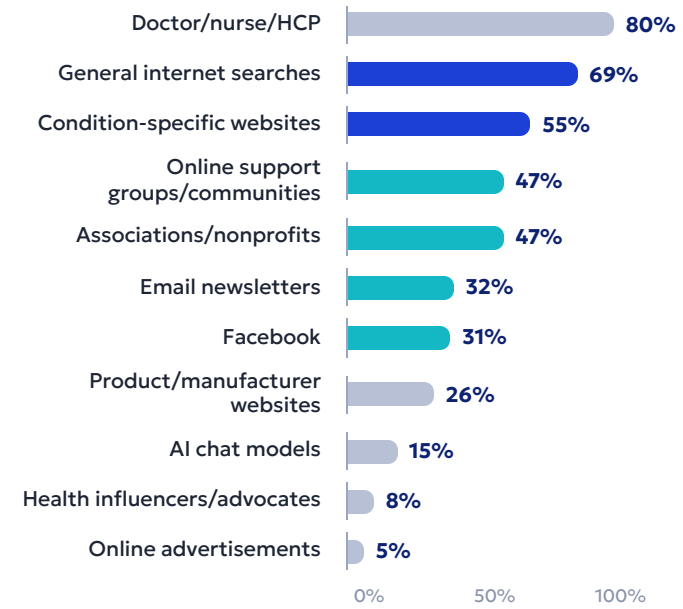
04 The Information Seekers: Proactivity in Search of Solutions

High Proactivity in an Underserved Market

Faced with limited clinical guidance, rare disease patients become active researchers. A notable **62%** actively seek out information about the latest medical advancements. Outside of clinical visits, **69%** rely on general web searches and **55%** turn to condition-specific websites.

Where Rare Patients Go to Learn

Sources currently used to learn about or manage their condition. Multiple responses allowed.



Base: Total sample (n=1,404)

REAL PATIENT VOICES: THE SEARCH FOR ANSWERS

> **I must do my own research to learn about new treatments. Isolation is also a big problem. I miss being able to physically meet others with this disease.**
>
> MYASTHENIA GRAVIS PATIENT

> **Multiple treatments have shown promise or gave me significant improvement, only to fail in less than 18 months.**
>
> MYASTHENIA GRAVIS PATIENT

When searching online, patients prioritize actionable scientific content. Their primary focus is exploring treatment options (**70%**) and understanding secondary complications (**60%**).

The Treatment Dissatisfaction Gap

33%	feel their condition is well-controlled on their current regimen	**35%**	plan to speak with their physician about changing their treatment plan in the next six months
83%	are open to clinical trials (28% interested, 55% would consider with more information). Patients only, n=1,325	**38%**	cite “not enough research on treatments,” the top barrier to optimal care

05 Strategic Roadmap for Rare Disease Marketers

To convert these universal patient friction points into meaningful brand engagement, commercial teams must ground their activation strategy in four key imperatives:

1
VALIDATE THE ODYSSEY
Acknowledge misdiagnoses and medical dismissals early. Provide symptom tracking tools that help patients advocate for themselves during clinical visits.

2
BRIDGE THE STIGMA AND KNOWLEDGE GAP
Develop educational resources for families, caregivers, and primary care physicians to build broader understanding and reduce social isolation.

3
DELIVER ACTIONABLE TREATMENT SCIENCE
Provide transparent clinical data, mechanism-of-action content, and trial information. Rare patients actively seek details on novel therapies.

4
REDUCE FINANCIAL AND LOGISTICAL FRICTION
Integrate robust co-pay, reimbursement, and lifestyle support directly into patient support programs to maintain independence and ease daily burden.

CONCLUSION

Turning Insights Into Actionable Partnership

Rare disease patients are not passive recipients of care; they are informed, proactive advocates forced to navigate complex health systems and social misunderstandings. By validating their journey, providing transparent science, and easing financial strain, brands can build lasting, trusted partnerships with rare patient communities.

Partner With Health Union

Health Union brings together authentic patient and caregiver experiences to help pharmaceutical brands clarify decisions and uncover strategic opportunities.

contact@health-union.com

Source: Health Union, Rare Disease In America 2026 (n=1,404 U.S. adults living with a rare condition or caring for someone who is; fielded Jan 12 to Apr 9, 2026). Patient quotes are lightly edited for spelling and length.

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