



bionews

Key Takeaways from the
**2024 Bionews Patient Survey:
Living with Rare Disease**

Living with a rare disease presents unique challenges. Every disease manifests differently, and the experiences of individuals vary greatly. By focusing on broad themes and shared challenges (*diagnostic and treatment journeys, and daily life experiences*), we can generate valuable data that will lead to more effective advocacy and support for all rare disease communities.

About Rare Disease

About 25–30 million Americans are living with rare diseases, which are conditions that affect a small percentage of the population. These diseases can be chronic, progressive, degenerative, and life-threatening, and patients often have complex care needs. Many people living with rare diseases face challenges in diagnosis, treatment, and access to care.

About the Survey

Bionews conducted an important nationwide initiative, the “Living with Rare Disease: 2024 Bionews Patient Survey,” to focus on the lived experiences of people with these rare conditions. The survey’s insights into diagnostic and treatment journeys, and patients’ daily life experiences, aim to enhance resources, support, and advocacy for all rare disease communities.

SURVEY DEMOGRAPHICS

Patient Demographics

98%

diagnosed with a rare disease.

Average diagnosis
9 years ago.

50% diagnosed
less than 6 years ago.

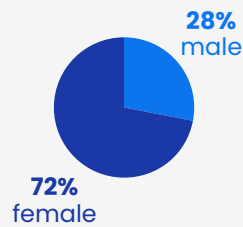
Methodology

- The survey was based on a national sample of **5,032 individuals living with a rare disease**, including **4,440 patients** and **592 family members** and **professional caregivers**
- Patients were recruited from BioNews’ websites, email lists, and social channels
- Survey was live Jan. 9–Feb. 13, 2024

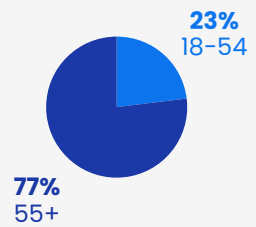
Overall Quality of Life

Patients want more research funding, greater awareness, improved access to treatment, and better support systems.

GENDER

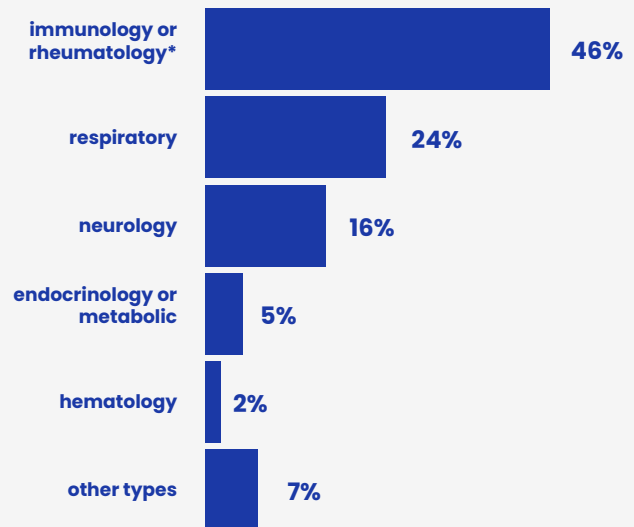


AGE



Over 40 rare diseases were represented by sample.

Breakdown of those diagnosed patients:



**Female and younger patients are more likely to have these diseases.*



Learn More

To view more survey details, including patient community opportunities and actionable solutions for pharmaceutical marketers and business leaders, contact Bionews SVP of Business Development, Ethan Ash, at ethan.ash@bionews.com.

Diagnosis Journey



Opportunities

- ✓ Raise disease awareness
- ✓ Provide educational resources
- ✓ Promote online tools
- ✓ Improve communication channels
- ✓ Increase emotional support

Time to Diagnosis

On average, it took **4.7 years** from the onset of symptoms for patients to receive a diagnosis.

For half of patients, it took **3+ years** to be diagnosed.

Many patients are misdiagnosed before receiving the right diagnosis.

Gender Differences in Diagnosis



5.2 years female
3.2 years male

Females experienced a longer diagnostic journey than males.

Females took an average of **5.2 years** to be diagnosed, compared to **3.2 years** for males.

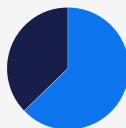
Females were significantly more likely to be misdiagnosed before their current diagnosis (**55% vs. 44% for males**).

Physician Experience

Diagnosed patients saw an average of **4.3 physicians** related to their symptoms before receiving a diagnosis.



72% of diagnosed patients ultimately were diagnosed by a specialist.



63% of diagnosed patients were satisfied with the communication they had with their healthcare providers during their diagnosis journeys.

Difficulties Faced



36% had problems related to finance/insurance, including out-of-pocket expenses for medications, doctors, testing, travel costs, and lost wages



40% faced access issues including lack of testing or specialists near them



32% dealt with long wait times for testing/specialists



33% faced lack of emotional support

Online Resources

67% of patients used online resources to aid in their diagnosis, including search engines, health information sites, online patient communities, and patient advocacy websites.

Online resources helped patients identify symptoms, learn about treatment options, and connect with other patients.

Need for Increased Awareness

80% of patients say lack of knowledge about rare diseases was a hurdle in diagnosis. Women (**81%**) faced this challenge slightly more often than men (**76%**).

Treatment Journey

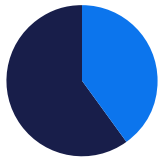


Gaps in treatment awareness and satisfaction: Many patients are unaware of available treatments, and a significant portion are dissatisfied with their current options, particularly female and younger patients.

Opportunities

- ✓ Increase awareness and availability of treatments
- ✓ Improve treatment satisfaction
- ✓ Develop patient support programs
- ✓ Address needs of specific patient groups

Medication Burden



40% of diagnosed patients are taking **more than 6 medications**, with an **average of 5.4 medications**.

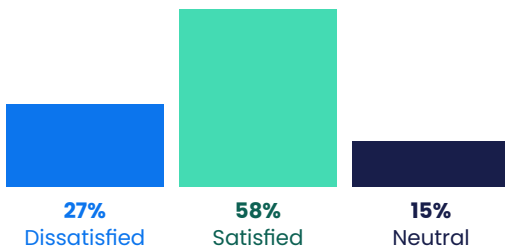
Lack of Awareness & availability of FDA-approved Treatments

21%

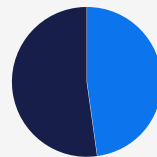
1:5 diagnosed patients are not sure if there is an FDA-approved treatment for their condition.

Females are significantly less likely to be aware of treatments than males.

Satisfaction with FDA-approved Treatments



Medication Switching



Almost half of patients (**48%**) are open to switching medications within the next year.

Common reasons for switching include: ineffectiveness of current treatment, physician recommendation, or a new drug approval.

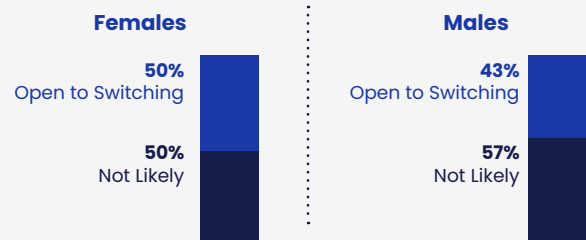
Complementary Medications and Support:

Many (**59%**) patients use medications to manage symptoms and improve their quality of life, in addition to FDA-approved treatments.

65% of patients are modifying their lifestyle while **31%** are using complementary and alternative therapies.

Gender differences

Female patients say they are more likely to switch medications within the next year.



Total Treatment Experience




61% of diagnosed patients are **satisfied** with their current comprehensive treatment plan.

Male patients are more likely to say they'd switch because a new drug is approved or expected to be approved.



Daily Life Experiences & Caregiving Relationship



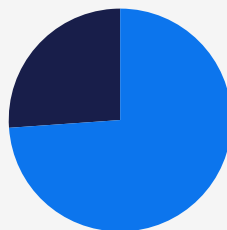
Opportunities

- Develop patient support programs
- Support for physical limitations among all patients
- Bolstering emotional and mental health among younger patients
- Supporting patients to better engage in daily and social lives/activities
- Tailor resources to specific patient groups

Impact of disease on daily activities



Over **3/4 (77%)** of patients say their disease has affected their ability to perform daily activities.



74% say their biggest challenge is physical limitations.

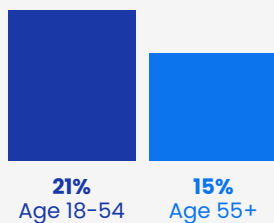
Female and younger patients are more likely to experience challenges in daily living due to their disease (e.g., pain, fatigue, unpredictable symptoms).

Emotional & mental health

1 in 6 (16%) say the biggest challenge is emotional/mental health.

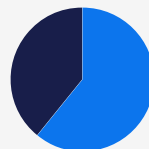


Younger patients are **1.4 times more likely** than older patients to say emotional/mental health is their biggest challenge.



Personal coping mechanisms

Personal coping mechanisms are the most helpful resource for managing daily life.



The majority of patients (**61%**) reported that personal coping mechanisms and strategies were helpful in managing their daily lives.

Online resources

Online resources and support groups are also valuable for many patients.

Online communities and forums (**52%**) and rare disease advocacy organizations (**30%**) were also seen as helpful resources.



Patient support groups (**23%**) and mental health counseling (**20%**) were used by a smaller but significant number of patients.



Caregiving

About **3 in 10 patients** have a dedicated caregiver, with most receiving care from family/friends rather than professionals.

Cost, availability, and finding the right fit are challenges faced by patients who need caregiving services.

Bionews' full range of available, condition-specific insights: Survey Respondent Sample Sizes

Amyotrophic lateral sclerosis	264
ANCA-associated vasculitis	243
Angioedema	38
Atypical hemolytic uremic syndrome	25
Charcot-Marie-Tooth disease	235
Cold agglutinin disease	96
Cushing's disease	73
Cystic fibrosis	73
Ehlers-Danlos syndrome	627
Fabry disease	36
Familial amyloid polyneuropathy	12
Friedreich's ataxia	27
Hemophilia	16
Huntington's disease	36
Hypoparathyroidism	47
Lambert-Eaton myasthenic syndrome	32
Muscular dystrophy	83
Myasthenia gravis	426
Myeloma	121
Neuromyelitis optica spectrum disorder	21
Other	193
Pompe disease	9
Porphyria	21
Pulmonary fibrosis	424
Pulmonary hypertension	172
Sarcoidosis	382
Scleroderma	548
Sickle cell disease	32
Spinal muscular atrophy	30
N	=4372*

*Patients, 18+ years old

About Bionews

Bionews is a digital health solutions company dedicated to empowering over 50 rare disease communities with trusted information, news, and connections. We foster a space where hope thrives and patients' voices are heard.

Since 2013, we've been committed to serving patients and elevating their voices. Our motto is "For Rare, By Rare." With over 50% of our team living with or caring for someone with a rare condition, we understand the unique challenges and needs of these communities. We've built a network of over 500,000 registered members actively seeking news, clinical information and sharing experiences. This creates a safe space for peer support, connection, and learning. Bionews offers a comprehensive platform serving a wide range of rare diseases, from larger condition specific communities like [Pulmonary Fibrosis](#) to smaller ones like [AADC](#).

Visit [Bionews.com](https://bionews.com) to explore our communities and discover how we're making a difference for the rare disease community.

Learn more

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