

Bionews Rare Disease Patient Journey: Insights from Largest US Survey Exposes Gaps and Opportunities for Improved Care

Bionews Launches Much-Needed Resources for Patients with Rare Disease to Close Resource Gap in this Patient Population

PENSACOLA, FL, USA, June 4, 2024 /EINPresswire.com/ -- [Bionews](https://www.bionews.com/), Inc., the nation's largest and most trusted network of online rare disease patient communities, unveils valuable findings from the largest-ever US survey of over 5,000 rare disease patients and caregivers. The "2024 Bionews Patient Survey: Living with Rare Disease" sheds light on the patient journey, revealing critical gaps and opportunities for enhanced care and engagement. Download the report highlights to learn more: www.bionews.com/rare-disease-insights/.

2024 Bionews Patient Survey Report: **Living with Rare Disease**

Bionews' inaugural "Living with Rare Disease" survey became the **largest ever conducted in this space, garnering over 5,000 completed patient surveys.**



2024 Bionews Patient Survey Report

Key Findings:

- **Diagnosis delays:** A staggering 4.7 years is the average wait for diagnosis, with females disproportionately affected by delays. Lack of awareness is the biggest hurdle, impacting 80 percent of patients.
- **Access challenges:** Access to specialists, testing, and specialists pose significant difficulties for a large portion of patients.
- **Treatment awareness and dissatisfaction:** Many patients are unaware of existing treatments, and a significant number, especially women and younger individuals, are unhappy with their current options.
- **The power of online resources:** The vast majority of patients rely on online resources for information and connection with others facing similar challenges.

Rare diseases present unique challenges for marketers to reach patients and their caregivers. By connecting patients, caregivers, and healthcare professionals, Bionews is at the forefront of



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Chris Comish, CEO of Bionews

finding solutions and supporting patients.

"The survey data provided a richer understanding of the challenges faced by patients, specifically in women, and particularly in diagnosis and treatment," stated Chris Comish, CEO of Bionews. "Bionews' approach emphasizes the importance of authentic and patient-centric community engagement and the power of [online communities](#) in driving advancements in rare disease therapies, along with resources to address unmet patient

needs. That is why this insight is compelling us to launch a dedicated series of resources to empower patients on their unique rare disease journeys."

About Rare Disease

Rare diseases are conditions that affect a small number of people, often with complex care needs. These diseases can be chronic, progressive, degenerative, and life-threatening. Rare diseases affect roughly 1 in every 10 Americans (approximately 7,000 rare diseases affecting between 25 and 30 million Americans) and there is a big unmet need in this community of resources and programs - with many facing challenges in diagnosis, treatment, and access to care.

About the Survey

Bionews conducted the "2024 Bionews Patient Survey", a nationwide, online survey of 5,032 rare disease patients and caregivers conducted between January and February 2024. The survey instrument included 48 questions designed to explore the patient experience across diagnosis, treatment, and daily life. The survey's findings, which reveal significant challenges and opportunities, aim to enhance resources, support, and advocacy for all rare disease communities. Download the report highlights to learn more: <https://bionews.com/rare-disease-insights/>.

About Bionews

Bionews is a digital health solutions company dedicated to empowering more than 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 more than 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 more than 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 including pulmonary fibrosis to smaller communities such as AADC.

Visit [Bionews.com](https://www.bionews.com) to explore our communities and discover how we're making a difference for those living with rare diseases.

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